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**Finding meaning after stroke:  
An analysis of Older People's stroke narratives**

**Susan C Ross**



DOCTORATE IN CLINICAL PSYCHOLOGY

THE UNIVERSITY OF EDINBURGH

MAY 2011

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“There is no greater agony than bearing an untold story inside you”

Maya Angelou

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*I dedicate this thesis to my Grandmother,  
who has unknowingly inspired so much of my work.*

## **V. ABSTRACT**

Little is understood about the process by which individuals maintain or lose a positive sense of wellbeing in the face of a chronic disabling condition such as stroke (Clarke, 2003). It appears that the impact of residual impairments and disabilities can pose significant problems for wellbeing in older adults, but the presence of such sequelae is not necessarily correlated with subjective wellbeing – some adapt well while others are devastated by minor sequelae (Clarke, 2003). Additionally, little is known about recovery in stroke survivors in relation to normal ageing processes (Green & King, 2007).

Through narrative we bring a sense of order to the disorder in our lives, and gain a sense of temporal continuity as we define ourselves in the context of our experiences (Murray 2008). A qualitative study examined the narratives of a sample of six older people with stroke in the East of Scotland. Participants took part in an episodic interview exploring their experience of stroke and the impact it has had on them and their lives. Narrative analysis was used to explore these stories. A story analytic approach was used to examine the content and structure of stroke narratives. A performative analysis revealed that narrative anchors relating to health, relationships, activity and ageing were used by participants to make sense of stroke, while stroke itself was an anchor point in participants' ongoing life stories. These findings were interpreted in relation to theories of ageing, suggesting that a developmental approach may be helpful in understanding the experiences of stroke survivors entering frailty, rather than focussing on the active ageing strategies which benefit those in the younger-old age groups. An approach similar to that used in working with grief is proposed as a framework to help health and social care staff and service users understand the process of adjustment following stroke.

## **VI. PREFACE**

### **VI.I Perspective of Researcher**

In qualitative research, researchers are encouraged to immerse themselves in participants' narratives and to remain close to the data (Murray, 2008). Bloomberg and Volpe (2008) state that "*In qualitative research, the researcher is the main research tool or instrument*" (Bloomberg & Volpe, 2008, pp23). The researcher brings their own knowledge, views, interpretations and unique style to each stage of a study. The final thesis combines views from the participants' lives with those of the researcher's life. It is, therefore, a collaborative narrative (Bloomberg & Vople, 2008).

As such, it is important that the reader is aware of my perspective and role as researcher. I had to make decisions on how to build this thesis, remaining true to myself and my methodology while meeting the academic requirements of a doctoral thesis. This preface lays out who I am and my clinical and personal motivation for undertaking this research.

To transparently convey my role throughout this thesis, the first person 'I' will be used, rather than 'the researcher' or 'the author'.

### **VI.II Clinical Motivation**

I am currently in my fifth year of the specialist training route of The University of Edinburgh's Doctorate in Clinical Psychology Programme. My training has comprised four years working half time with the Older People's Service within the NHS Fife Psychology Department alongside six clinical placements.

In 2007, during my third year, I undertook a placement in the Older People with Stroke Service in NHS Fife. This entailed working with staff and families as well as stroke survivors themselves. Much of this clinical work was around helping those who have had a stroke make sense of their experiences and the changes in their lives. I was perplexed by how some people seemed to make a good recovery and despite functional limitation saw life as richer, while others were devastated by the effects of

stroke. Throughout this year, I felt that there was something about the experiences and the process these clients were working through that I could not find a satisfactory theoretical explanation for.

My exploration of qualitative studies led me to take a step back from my attempts to explain my observations and begin to ask questions instead. Much of the current literature relates to the experiences of being a stroke patient or stroke survivor, and to the functional impact of stroke on life. Reading about narrative studies I took a further step back. I realised that, rather than imposing my subjective assumptions of what was important and my interpretation of what I was hearing, I should attempt to capture some stories and examine them methodically and transparently to begin to understand what I was observing.

### **VI.III Personal Motivation**

At the outset of this thesis, I feel that it is important to draw attention to my longstanding affinity to the process of ageing and the changes that arise both through ageing as well as illness. I had an exceptionally close relationship with my Grandmother and throughout my childhood and early adulthood I witnessed my Grandmother's ageing, illnesses and death with admiration for how she evolved as a person. I recall asking her as a child why she had wrinkles and her explanation of life taking its toll on the body, and wrinkles representing all the stories you have to tell. As she grew older, one of her greatest fears was having a stroke. Even as I write this I am filled with emotion, with treasured memories entwined with sadness and a sense of inadequacy that I did not understand more at the time. I think about how my own career choice and specialist interests, my sense of self and awareness of my own mortality have been influenced by this precious relationship.

One particular observation I made on many occasions with my Grandmother was the language she used. She frequently talked about the death of an ill, elderly friend by using the phrase, "*She got away.*" There was a different meaning to this than the commonly used phrase, "*She passed away*", in that it was something that the person had been waiting for. This was in stark contrast to the tragedy that she talked of when hearing of a younger person's death. This different perspective towards life and

death as reflected in my grandmother's language was something that I could not quite understand in my late teens and early 20s.

Another observation was her delight at hearing stories of what I had been doing and how she almost lived them herself as she heard what I told her. I recall wondering if I was being unfair going to visit her in her nursing home and telling her all of the things I had been doing when she was no longer able to get out and about. However, after my Mother drew my attention to her delight in my stories lifting her mood for weeks after my visits, I eventually understood that she was living vicariously through these stories.

These experiences have undoubtedly influenced my work so far and play a role in the manner in which I have approached this research. Memories flooded back to me as I listened to some of my participants telling me their stories, and as I listened to the recordings afterwards I felt a whole range of emotions. I have kept a reflective log throughout the research process to allow transparency of what I bring to the analysis. Rather than quoting extensively from my memos, I have included my voice throughout this thesis. I feel that I have captured something special in these interviews and hope that this thesis helps to make sense of my participants' sense making.

# **1 INTRODUCTION**

## **1.1 Chapter Summary**

Chapter 1 outlines the relevant background to this thesis, beginning with setting the current context of stroke as a long term condition. The current knowledge about the impact of stroke in the short and longer term is laid out. A brief review of the literature on ageing is presented, prior to an introduction to narrative. The chapter concludes with the aims and scope of this research.

## **1.2 Stroke as a Long Term Condition**

### **1.2.1 Demographic change**

The UK population is ageing, with current projections indicating that the number of people over 65 is likely to increase from 9.7 million in 2006 to 12.9 million by 2021 (Office for National Statistics, 2008). As well as people living longer, medical advances mean that people are living longer with illnesses (British Medical Association, 2006). These demographic changes increase both the demand and the nature of the support required in this sector of the population.

### **1.2.2 Long term conditions in an ageing population**

Long Term Conditions (LTCs) is the term used to collectively describe health conditions that cannot at present be cured, but can be controlled by medication and other therapies (British Medical Association, 2006). LTCs include diabetes, asthma, chronic obstructive pulmonary disease (COPD) and stroke. Those living with LTCs often live with discomfort and stress and many require support with activities of daily living (Department of Health, 2010).

The number of people living with a LTC is expected to rise due to unhealthy lifestyle choices, an ageing population with increased life expectancy and improvements in acute medical care (Department of Health, 2010). As prevalence rates for many LTCs are increasing there is a growing burden on services. Those with LTCs make frequent contact with their GP, are more likely to be admitted to hospital and stay in hospital longer than those without LTCs (Department of Health, 2010).

Improvement of care for those with LTCs has been identified as a priority (Department of Health, 2004). The Long Term Conditions Agenda refers to a cluster of policies which collectively aim to provide patients with the most intensive treatments in the least intensive setting. This includes patients with neurological conditions such as stroke (Department of Health 2005b; Scottish Government, 2007).

Traditional acute health care models have focussed on providing reactive care during the acute phases of illness, responding when conditions reach crisis point. This often



entails hospital admissions and heavy use of secondary care services. As more people are living for longer with LTCs there is more need than ever before to provide a systemic patient centred approach providing ongoing coordinated support to minimise such crises occurring. This model of care should offer personalised care plans matching support with need, based in primary care settings, with effective and timely communication across the entire health and social care spectrum (Department of Health, 2004; 2005a; 2005c). Systemic changes are required in order to implement such shifts in service provision so that those receiving and delivering services have both the confidence and capacity to work collaboratively (Scottish Government, 2008). The three main focus areas of sustainable improvement are: self management, condition management and complex care/case management (Department of Health, 2005a; Scottish Government, 2008).

### **1.2.3 What is stroke?**

A cerebrovascular accident, or stroke, is a “*focal neurological deficit (loss of cognitive function affecting a specific region of the nervous system) due to disruption of its blood supply*” (World Health Organisation, 2010). The disruption of blood supply deprives the brain of oxygen and nutrients, which causes damage to the brain tissue (SIGN, 2008).

There are various mechanisms by which this disruption in blood supply can occur. Most strokes are caused by blood vessels being blocked by a cerebral thrombosis or embolism (clot), known as ischaemic stroke. This results in the permanent death of brain tissue and loss of associated function (SIGN, 2008; Bellg, 2004).

Ten to twenty per cent of strokes are caused by a ruptured blood vessel, causing haemorrhage, which tend to have more transient effects (Bellg, 2004, Stroke Association, 2009a). This bleeding can occur inside the brain, or inside the skull but outside the brain tissue itself. For example, subdural stroke occurs when blood leaks into the area between the skull and the dura, which is a thin layer of tissue that separates the brain from the skull. This can increase the pressure inside the skull and compress the brain, causing damage to the brain tissue and, if untreated, other forms of stroke (Stroke Association, 2009a).

The severity of stroke falls on a continuum. Historically, when all symptoms of an interruption to the blood supply to the brain resolve within 24 hours, it is known as a transient ischaemic attack (TIA) (SIGN, 2008). However, approximately half of reported TIAs resolve fully within 30-60 minutes, while the other half lead to permanent damage to brain tissue. As such the terminology is not applied consistently in practice and there are proposals to amend the definition of TIAs (Albers *et al.*, 2002; SIGN, 2008).

The location of stroke is important. Blood vessels involved in ischaemic stroke can be involved in delivering oxygenated blood to a vast area of brain tissue, or to a relatively small area. There are common patterns of impairment depending on the location of the vascular event. The Oxford Community Stroke Project classification (OCSP) is often used to classify the initial symptoms of ischaemic strokes which can offer predictions about the extent and location of the stroke, the underlying cause and prognosis (Bamford, 2000).

#### **1.2.4 Prevalence of stroke**

It is estimated that approximately 80 per cent of first-ever-in-a-lifetime strokes (FES) occur in those aged 65 or over. Stroke is the third leading cause of death in this population in Scotland and the most common disabling condition (SIGN, 2008). It is estimated that there are 8500 FES in Scotland each year. Approximately two thirds of people who suffer a stroke survive and require some level of rehabilitation (National Institute of Neurological Disorders and Stroke, 2002).

Given that mortality rates after stroke have declined with improvements in acute medical care and the demographic changes in population, the number of people aged over 65 living with stroke is rising and it is likely to become an increasingly important issue for therapists working with older people (Laidlaw, 2008).

#### **1.2.5 The course of stroke**

Stroke has a sudden onset, often with no warning. Statistics suggest that one third of strokes result in death within ten days; another third are likely to make a recovery in one month; the final third are likely to be left disabled and requiring rehabilitation.

However, there is no predictable course of the illness, with a high likelihood of recurrence (Stroke Association, 2010).

Stroke survivors, their families and carers live with many uncertainties surrounding rehabilitation potential and the unpredictable course of stroke. Although vascular risk factors can be monitored and treated in attempt to reduce the chances of stroke re-occurring, stroke can happen again at any time with little or no warning (Stroke Association, 2008b). One study found that in a sample of 675 FES survivors who were followed up for six and a half years, the risk of recurrence was 30 per cent by five years. The risk was highest soon after the first stroke with thirteen percent having a further stroke within one year (Burn, *et al.*, 1994).

### 1.2.6 The acute phase of stroke

There are two distinct phases of stroke - acute and rehabilitation. The acute phase, or time of onset is characterised by a **sudden** onset of symptoms including:

- Weakness or numbness of the face, arm or leg on one side of the body
- Loss or blurring of vision, in one or both eyes
- Difficulty speaking or understanding spoken language
- Confusion
- Severe headache with no apparent cause
- Dizziness, unsteadiness or a fall

(Stroke Association, 2010)

These symptoms have been widely publicised in the recent Stroke Association (2008b) campaign. This health promotion campaign describes the symptoms of stroke using the term 'brain attack'. The parallel with heart attack has aimed to increase awareness in the general public of stroke as a medical emergency. The campaign has used the FAST mnemonic, representing the Facial weakness, Arm weakness, Speech problems and Time to call 999 (Stroke Association, 2008). This was adapted from an assessment scale developed by Harbison *et al.* (2003), an example of professionals and service users beginning to share a common language.

Prompt medical attention can limit the damage caused by stroke. As such, National clinical guidelines on the management of patients with stroke or TIA in the acute

phase make recommendations regarding the system of care, assessment and evidence based interventions. A care pathway is outlined from the onset of a suspected stroke to the assessment, management and treatment, as well as monitoring and prevention of recurrent stroke (SIGN, 2008).

Ambulance priority is recommended for suspected stroke cases. To aid this rapid assessment various standard assessment scales can be used which display acceptable accuracy when used by paramedics, for example FAST. On arrival, suspected strokes should be rapidly triaged and if stroke is confirmed, immediate access to specialist stroke services should be available. These services should provide rapid brain imaging and specialist assessment by a multidisciplinary team (SIGN, 2008; SIGN, 2010). There are a range of evidence based interventions available and treatment should begin promptly (SIGN, 2008).

Risk of recurrence is assessed early, considering risk factors such as age, blood pressure, clinical features, duration of symptoms and a history of diabetes. When high risk of recurrence is identified early preventative interventions can be administered which have been shown to reduce death, disability and recurrent stroke, as well as improve likelihood of full recovery in patients with ischaemic stroke (Amarenco *et al.*, 2006; Sandercock *et al.*, 2008).

Management of other risk factors in the longer term may require significant lifestyle changes. A combination of such changes has been shown to reduce the recurrence rate by up to 80 per cent (Hackam & Spence, 2007). These changes include a diet low in total and saturated fats, reducing dietary salt, increasing consumption of fruit and vegetables, achieving and maintaining a healthy weight, moderate exercise, limited consumption of alcohol and cessation of smoking (SIGN, 2008).

Often information is provided regarding interventions to promote lifestyle change during the acute phase. The FRAMES model of behavioural change is recommended to promote such changes in behaviour, which is based on motivational interviewing and stages of readiness to change (Miller & Spilker, 2003).

**Feedback** – Patient receives information about current status  
**Responsibility** – Patient assumes responsibility for change  
**Advice** – Patient receives suggestions that will help him or her in the change process  
**Menu** – Patient receives a number of alternative strategies for modifying the problem behaviour  
**Empathy** – Patient receives warm support and respect  
**Self Efficacy** – Patient develops an “I can do this” attitude

**Figure 1.1 The FRAMES model of behaviour change (Miller & Spilker, 2003)**

Recommendations state that during this time stroke patients and their carers should be provided with information, support and training in a variety of accessible formats. This should be tailored to each individual’s need, based on their readiness to receive information and the phase of their recovery (SIGN, 2008).

However, this acute phase of stroke is associated with high levels of fear and uncertainty (Stroke Association, 2010). While this information provision goes some way to alleviate some uncertainty regarding the care system and can offer practical advice, the psychological impact of stroke in the short term is wide-ranging (Stroke Association, 2010) and may in fact limit both patient and carer ability to make sense of such information.

### **1.2.7 The rehabilitation and adjustment phase of stroke**

Advances in acute medical care described above along with increased public awareness highlighting the urgency of receiving medical attention have reduced mortality (Stroke Association, 2008b). However, this has led to increasing survival rates and a corresponding need to reduce morbidity in the longer term. This second phase of rehabilitation and adjustment is examined below.

The nature and severity of the effects of stroke are wide ranging. Some function may improve with rehabilitation, while other functions may not be regained (Mitchell *et al.*, 2008). The damage to brain tissue caused by stroke can result in impaired

physical function, including paralysis as well as loss or distortion of higher-order functions like language, memory and personality. Automatic function such as swallowing, speech and continence can also be altered (Stroke Association, 2008a). Pain is common after stroke. Stroke patients often experience fatigue, which can limit their ability to take part in rehabilitation activities, and reduce their overall activity level (SIGN, 2010). Visual problems associated with stroke are common and often complicate existing age-related visual problems (SIGN, 2010).

Stroke often results in impairment in communication (Stroke Association, 2008a; Thomas & Lincoln, 2008). Such impairments can take a variety of forms and are commonly referred to as Dysphasia. This is defined as impairment in producing or comprehending spoken or written language while other cognitive abilities remain intact (Thomas & Lincoln, 2008).

The Stroke Association define rehabilitation as “*the process of overcoming or learning to cope with the damage the stroke has caused*” (Stroke Association, 2008a:5). This means returning to normal life as far as the lasting effects allow, and achieving the maximum level of independence through relearning old skills, learning new skills, adapting to limitations and putting the necessary supports in place to enable this (Stroke Association, 2008a). This includes assessment and quantification of need, and subsequent setting of short, medium and longer term goals. Intervention is tailored towards achievement of these individualised goals with continuous re-assessment comparing progress with the agreed goals (SIGN, 2010). Early mobilisation is recommended, with physiotherapy and occupational therapy to promote activities of daily living, including standing, walking and upper limb function (SIGN, 2010). However, fatigue and psychological factors often limit stroke patients’ ability to engage with these services.

### **1.2.8 Summary of stroke as a long term condition**

Health and social care systems are required to evolve in order to meet the changing needs of the ageing population, such as the increase in LTCs like stroke. Service providers have to work collaboratively with those living with LTCs to facilitate self management. This requires not only service providers understanding the disease processes themselves, but also understanding the psychological impact of living with such illnesses in the short and longer term. This will enable them to both deliver better care and empower patients to maintain their optimum wellbeing.

## **1.3 The Longer Term Impact of Living With Stroke**

The impact of stroke described in section 1.2 predominantly arises from research taking a medical or functional perspective, for example the long term functional impact of stroke (Lai *et al.*, 2002) or relating to functional rehabilitation (e.g. Gubrium *et al.*, 2003; McIntyre & Mitchell, 2009). However, it is important to consider the experiences of stroke patients living with the lasting effects of stroke.

A recent audit (Correia, 2008) revealed that the type of referrals received by the Older People with Stroke Service in Fife generally fall into two broad categories. Firstly there are those relating to rehabilitation, such as depression and anxiety limiting a patient's ability to participate in their rehabilitation programme. Secondly are those relating to poor adjustment in the years following stroke, for example, often leading to depression and anxiety. This pattern of help seeking highlights the need to further understand the longer term impact of stroke.

### **1.3.1 Post-stroke adjustment**

Patient perspective and quality of life are increasingly being explored in stroke care (e.g. Carod-Artal *et al.*, 2008). Such studies indicate that the process of adjustment following stroke is complex. It has long been recognised that an individual's perception of a situation determines adjustment in terms of behaviour and feelings, rather than objective situations (Clarke, 2003). Quality of life is determined by an individual's life satisfaction, self esteem and perceived control, rather than the health or environmental parameters they live within. An individual's goals and meaning systems are reflections of these perceptions and evaluations (Coleman, 1999).

Regardless of the outcome of stroke, even a minor stroke signals to the patient that he or she could have died and that relapse may occur at any time (Hjelmblink & Holmstrom, 2006). As would be expected, this results in distress in many stroke patients (Thomas & Lincoln, 2008). It is widely recognised that the acute onset of stroke presents problems for adjustment following a sudden and rapid loss of function (Woods, 1999). This uncertainty, combined with the functional changes



that may have resulted from stroke paint a bleak picture for stroke survivors, yet many adjust to their changed situation and seem to thrive (Clarke, 2003).

Little is understood about the process by which individuals maintain or lose a positive sense of wellbeing in the face of a chronic disabling condition such as stroke (Clarke, 2003). It appears that the impact of residual impairments and disabilities can pose significant problems for wellbeing in older adults, but the presence of such sequelae are not necessarily correlated with subjective wellbeing – some adapt well while others are devastated by minor sequelae (Clarke, 2003).

Attitudes and beliefs of stroke survivors and their carers can affect recovery (SIGN, 2010). A study by Townend *et al.* (2010) found that personal beliefs about acceptance of post stroke disability were associated with and predicted emotional adaptation following stroke. They looked at the association of acceptance of disability with post stroke depression (PSD) using a prospective cohort mixed qualitative and quantitative design. Similar to previous studies, one third of participants were found to have depression one month post stroke and thirty per cent after nine months. Non-acceptance of disability was associated with depression when age, gender, stroke severity and current disability were controlled for. The qualitative findings demonstrated that non-acceptance of disability had self-reproachful elements, with depressed patients often referring to themselves as ‘*useless*’ and that they ‘*should still*’ be capable of carrying out the activities their disabilities limited. In contrast many of the patients who were not depressed reported accepting the disability resulting from their stroke (Townend *et al.*, 2010).

How this process of adjustment, the lasting psychological consequences of stroke and the role of stroke all impact on an individual’s ongoing development, life story and ageing is yet unknown (Lai *et al.*, 2002). This has been highlighted more recently in the SIGN guidelines which lay out recommendations to support the rehabilitation phase of stroke (SIGN, 2010). While there appears to be little evidence supporting psychological therapy following stroke at present, this lack of evidence must not be interpreted beyond a lack of research. Examining the impact of stroke by exploring wider psychological consequences, and the process of adjustment may

enable the issue to be explored in a manner other than looking for major mood disorder such as depression.

### **1.3.2 The psychological impact of stroke**

#### *Cognitive changes:*

Stroke can result in a multitude of cognitive changes. These may be general, such as slowing of information processing, or more specific. Specific cognitive impairment can include difficulties with orientation, attention, memory, visuo-spatial perception, mental flexibility, planning and organisation and language. A lack of insight into difficulties is also common (SIGN, 2010). As well as the long term impact, these difficulties have implications for rehabilitation, in terms of understanding instructions, adhering to treatment plans and risk management procedures.

#### *Mood and behaviour changes:*

Stroke has a multitude of psychological effects. Research has examined how such effects may be directly caused by damage to the brain. For example, emotional lability, which occurs in approximately ten per cent of stroke survivors, seems to arise from damage to a specific area of the brain (Stroke Association, 2009b; SIGN, 2010). There are also wide ranging psychological consequences of stroke. These reflect the impact of the experiences the person with stroke has during the acute phase of their illness, rehabilitation and as they adapt their life to accommodate the changes in their functioning (Murray & Harrison 2004).

#### *Post stroke anxiety problems:*

Anxiety is commonly reported following stroke. One study found that 28 per cent of a population-based cohort of 80 patients with acute stroke had generalised anxiety disorder in the acute stage. At three months post stroke, 31 per cent of 70 met this criteria and after one year 24 per cent of 66 (Åström, 1996). Many people have realistic fears of recurrence and concerns about how life will change after their stroke. It is commonly reported that stroke patients worry about being a burden on family members. These fears can lead to avoidance, for example resulting from fears

of overexertion inducing another stroke, or fears of falling (Stroke Association, 2009b).

The sudden and unpredictable onset of stroke as a life-threatening stressor has been linked with Post Traumatic Stress Disorder (PTSD). In one study, 62 FES patients were screened and those reporting any symptoms of PTSD took part in a structured clinical interview. Six of these patients (9.8 per cent) fulfilled the criteria for PTSD. There were no significant differences between these six patients and the rest of the sample in terms of premorbid factors. The authors conclude that PTSD or a PTSD-like syndrome can occur after stroke (Sembi *et al.*, 1998).

While it is almost assumed that stroke survivors will experience worries and uncertainty, there is evidence of complex and wide-ranging manifestations of anxiety based difficulties following stroke. Health and social care staff should be vigilant for such idiosyncratic presentations and how they relate to premorbid functioning.

#### *Post stroke depression:*

The lasting effects of stroke often include limited activity levels due to disability and fatigue. This can lead to social isolation, increased dependence on family, friends and services, and a reduction in participation in pleasurable and meaningful activities (Pohjasvaara *et al.*, 1998). There is a high rate of comorbidity in stroke survivors, such as hypertension and heart failure. Only 15 per cent of stroke survivors in Scotland experience stroke alone, with 25 per cent having one other LTC and 60 per cent having two or more other LTCs (NHS National Services Scotland, 2008). Stroke is also associated with other life events, including falls, deaths of spouse/friends or moving house (Broomfield *et al.*, 2010). It is therefore hardly surprising that depression is a frequent consequence of stroke.

Reported prevalence rates of post-stroke depression (PSD) range from 25 per cent to 79 per cent (Gordon & Hibbard, 1997). Recent research suggests that in the twelve months following the onset of stroke one in three stroke survivors develop PSD (Hackett *et al.*, 2009). However, it is widely recognised that there are clear links between depression and disability in later life and high levels of sub clinical

depression in the older adult population. It is therefore likely that the actual prevalence of PSD is high. The impact of stroke may be magnified by the symptoms of depression. Such excess disability arising from poor adjustment results in additional supports being required, which adds to the financial cost of stroke as a LTC (Laidlaw, 2008).

PSD has been shown to hinder functional recovery as discussed previously. This may be due to a lack of motivation and hopelessness limiting the ability to engage with rehabilitation programmes (Pohjasvaara *et al.*, 2001).

There is little evidence at present to suggest that prophylactic prescription of antidepressant medication or one-to-one psychological therapies are effective in the prevention of post-stroke depression. However, principles from motivational interviewing and problem solving have been shown to be beneficial in education and rehabilitation goal setting (SIGN, 2010). There is also evidence that antidepressant medication is beneficial in treatment of post-stroke depression.

There have been few studies looking at the evidence supporting talking therapies, which have all produced mixed findings (Lincoln *et al.*, 1997; Lincoln & Flannaghan, 2003; Rasquin *et al.*, 2009).

Lincoln *et al.* (1997) piloted a CBT intervention with 19 stroke survivors who were diagnosed with major depression. Outcome was assessed using the Beck Depression Inventory (BDI; Beck *et al.*, 1996) and the Hospital Anxiety and Depression Scale (HADS; Zigmond & Snaith, 1983) and clinical interview. Four participants' outcomes were consistently improved with CBT, six showed some improvement, while nine showed no benefit. The authors concluded that CBT may be effective for PSD. Broomfield *et al.* (2010) highlight several limitations of this study, including the small sample size, and the lack of clarity as to the experience of the therapists, whether the intervention was manualised and whether supervision was received. Lincoln and Flannaghan (2003) followed this pilot up with a randomised controlled trial of CBT for PSD. Participants were randomly allocated to one of three treatment options: 10 sessions of CBT, 10 sessions of attentional control interviews comprising of supportive discussions, or treatment as usual. The 123 participants, recruited one

month post stroke were assessed using the BDI (Beck *et al.*, 1996), the Wakefield Depression Inventory (WDI; Snaith *et al.*, 1971) and Schedules for Clinical Assessment of Neuropsychiatry clinical interview (SCAN; Wing *et al.*, 1990) at three and six months. There were no differences between the three conditions. Broomfield *et al.* (2010) argue that methodological limitations may account for the null effects, including a limited number of treatment sessions with no formal evaluation of the quality of CBT and a small sample size at follow up. They also note that participants were selected from the stroke register so there was no indication of cognitive suitability or motivation to change prior to inclusion (Broomfield *et al.*, 2010).

Broomfield *et al.* (2010) argue that outcome research on CBT for PSD is at an early stage and propose that the characteristics of CBT suggest that it ought to be effective at addressing some of the difficulties experienced by those who are depressed following stroke. This includes CBT strategies to help with emotion regulation, increasing activity to optimal levels and promoting realistic yet optimistic thinking. This is consistent with suggestions by Dick *et al.* (1999) that the stressors that depressed older people with chronic illnesses face seem appropriate for intervention with CBT. Behaviourally, there can be a loss of independence and disability; cognitively, enduring illnesses often evoke thoughts about usefulness and uncertainty about the future; physiologically, there is often pain and discomfort; emotionally, depression, anxiety, and anger, for example (Dick *et al.*, 1999).

Rybarczyk *et al.* (1992) describe barriers to the application of CBT for those with LTCs. Barriers to initiating and engaging with treatment, include acute flare-ups, mobility difficulties and busy schedules with medical appointments and care support. CBT could promote assertiveness in clients, encouraging them to strive for the long term benefits of ensuring their needs are met. Another barrier to engagement is that depression is often perceived as a side-effect, or inevitable consequence of living with a LTC, so people feel resigned to endure it rather than seeking help. CBT can educate clients about depression and challenge such beliefs, enabling the depression itself to be addressed. CBT can also challenge negative and hopeless thoughts that may limit engagement. Beliefs about interpersonal relationships, such as feeling a

burden to others can be challenged and cognitive and behavioural interventions aim to promote functional independence (Dick *et al.*, 1999). Broomfield *et al.* (2010) propose augmented and individualised CBT taking into consideration the specific needs of this group and the above barriers. Suggestions draw on proposals made by Laidlaw *et al.* (2003) and Laidlaw (2008), including challenging baseline distortions whereby patients' comparisons with their premorbid abilities lead to anxiety, hopelessness, apathy and frustration. Comparison with functioning immediately after stroke can help promote hope and a sense of achievement.

### *Recovery*

Various studies have explored the experience and impact of stroke in terms of recovery. Olofsson *et al.* (2005) examined the experience of stroke patients regarding falling ill, their stay in hospital, their discharge and homecoming. They found three distinct phases in the recovery process: feeling “*responsible and implicated*”; a feeling of being a “*depersonalised object for caring measures*”; striving for “*repersonalisation and autonomy*” (Olofsson, *et al.*, 2005, pp433). This begins to offer insights into the experience of life following stroke, however as this study interviewed participants four months post stroke, the longer term impact remains unclear.

#### **1.3.3 Coming to terms with change**

Dowswell *et al.* (2000) found that recovery following stroke is often perceived in terms of the degree of congruence patients identify between their lives before and after stroke. When comparing life after stroke with how it was before, it is apparent that many stroke patients experience a variety of losses. Additionally, in clinical practice this population identify loss as highly relevant, and subsequently, models of loss are often used to inform formulation.

Kubler-Ross (1969) describes five stages of grief, which are commonly applied to other situations of loss beyond bereavement. These are *denial*, *anger*, *bargaining*, *depression* and *acceptance*. Parkes (1970) describes four phases of mourning, or the process of adjusting to the loss. *Numbness* is whereby the reality of the loss is

disregarded, and is similar to Kubler-Ross's term denial. The next phase is *yearning* for the lost one to return and denial of the permanence of the loss, which is often accompanied by anger. *Disorganisation and despair* follow this, whereby it is difficult to function in the environment. The final phase described is *reorganised behaviour*, whereby life begins to be pulled back together. These stages or phases overlap and are rarely discrete, however they are somewhat descriptive in nature (Worden, 2001).

Worden (2001) extends the descriptions of the commonly reported and observed stages or phases of grief and mourning to describe tasks of mourning. These are: "*to accept the reality of the loss; to work through the pain of grief; to adjust to an environment in which the deceased is missing* (internal, external & spiritual adjustments); *to emotionally relocate the deceased and move on with life*" (Worden, 2001, pp27-35). These conceptualisations of loss are often applied beyond grieving a death and can be useful clinically to explore functional or emotional losses too.

Grief counselling involves supporting those experiencing a normal yet painful process, conceptualised above as completion of the tasks of mourning, within a reasonable time frame. Grief therapy on the other hand is a clinical intervention aimed at identifying and resolving the conflicts of separation which prevent the completion of mourning tasks. This is appropriate when grief is absent, delayed, excessive or prolonged (Worden, 2001). A review of published randomised controlled outcome studies of both grief counselling and grief therapy revealed some evidence that grief therapy was beneficial for those with complex reactions. However, grief therapy was found to be ineffective, with possible iatrogenic effects in those experiencing normal bereavement (Neimeyer, 2000).

Loss is often associated with old age as many older people experience multiple losses arising from the death of friends and family, as well as work, home, health, independence and mobility. Yet, despite the increasing encounters with loss associated with ageing, older adults tend to experience fewer severe grief reactions and show lower levels of distress and mental health problems (e.g. Breckenridge *et al.*, 1986; McKiernan, 1996). Woods (1999) suggests that rather than older people

experiencing less grief, it may be the case that grief is expressed differently. For example, there may be a different time course with a longer recovery time. It is also widely recognised that emotions often present as physical symptoms in older people. Additionally, older people tend to seek less help than younger cohorts, with presenting demand for mental health services being much lower than in under-65 services (Woods, 1999). As such, the difficulties experienced by grieving older people may be underestimated.

While the loss models provide a framework by which some of the experiences of stroke survivors can be understood, this conceptualisation of the impact of stroke as loss does not adequately capture the complexity of the experience and therefore is insufficient in informing and guiding clinical intervention with these clients. Stroke survivors often identify a multitude of gains along with losses, such as insight into the fragility of life and an increase in forgivingness (Allemand, 2008).

Older people often report adapting well to changing circumstances (Coleman, 1999). Experiences and changes are often revealed in the stories people tell about their stroke - their narratives - which are used to regain coherence and confidence in life (Hjelmblink & Holmstrom, 2006). Narratives can be examined to begin to understand how stroke survivors make sense of their experiences as they adjust to their new circumstances, taking on new perspectives or frames of reference, incorporating their past with the person they are now (Hjelmblink & Holmstrom, 2006).

#### **1.3.4 Summary of the longer term impact of living with stroke**

The process of adjustment following a stroke is complex and as yet poorly understood. There is evidence of anxiety and depression following stroke. While there is as yet no clear evidence of the efficacy of psychological interventions, there are further avenues yet to be explored. Individual attitudes and perceptions seem to play an important role in how stroke survivors make sense of the multiple changes and losses they often experience, but the mechanisms of this process is unclear.



## 1.4 Qualitative Studies of Stroke

As discussed in section 1.3, examining the impact of stroke by measuring outcome in terms of predetermined questions regarding physical functioning or functional ability does not tell us about what stroke and recovery mean to the individual survivors themselves (Salter *et al.*, 2008). Multiple approaches are needed to understand stroke from a range of perspectives in order to provide services which meet the physical, emotional and social needs of stroke survivors. Qualitative research adds a dimension grounded in the experience of stroke survivors, so adding to the ability to deliver such services (McKevitt *et al.*, 2004). A number of qualitative studies have examined individuals' perspectives of their lives after stroke.

Current methods of assessing progress after stroke have been criticised due to a lack of consideration about what recovery actually means to patients (Dowswell *et al.*, 2000). A review of published qualitative literature on patient's experience of stroke by Hafsteinsdottir and Grypdonck (1997) revealed discrepancies between patient and professional rehabilitation goals. Their findings suggest that patients often have clear goals in relation to meaningful functional abilities, which are used to determine rehabilitation progress. As such, patients' views of recovery are often as a return to how life was prior to stroke. In contrast, health care providers measured recovery in terms of isolated and discrete skills being regained, rather than the return to previously valued activities. This review also highlights the psychological and social impact of stroke as being immense, with stress being experienced on many levels, including social functioning. They also draw attention to the high prevalence of depression in stroke survivors. While this early review of qualitative studies begins to pool the diverse qualitative literature on stroke, it only included four studies on the experience of being a stroke patient and the authors conclude that further qualitative studies are required to provide further insights into the experience of being ill with stroke and the process of recovery (Hafsteinsdottir & Grypdonck, 1997).

Burton (2000) looked at the experience of stroke and recovery taking a phenomenological approach, tracking six stroke survivors in a rehabilitation unit for at least twelve months following their stroke. This involved seventy three

interviews. The findings suggest that recovery involves restructuring and adapting in physical, social and emotional features of life. Pre-stroke life was used as a benchmark against which individual progress was compared, although no end-point to recovery was identified, which is in slight contrast to the findings of Hafsteinsdottir and Grypdonck's (1997) review which identified a return to pre-stroke function as the end point in recovery that stroke survivors strove for. In addition, the participants highlighted the social context of recovery, where social engagement was emphasised over physical function. Such findings suggest that stroke services should reflect the long term needs of stroke patients and their families in their home environment (Burton, 2000).

McKevitt *et al.* (2004) carried out a systematic review of published qualitative studies with the aim of considering their relevance to the development and delivery of services for people with stroke and to make recommendations for future research. The European Stroke Initiative (EUSI) recommendations for stroke management (Hack *et al.*, 2003) were used as a guide of clinical excellence against which the studies were mapped. Ninety five published articles were identified through online database search. Those accepted concerned the "identification of needs as perceived by patients and their families, differences in priorities between patients and professionals, and barriers to best-quality care" (McKevitt *et al.*, 2004, pp1499).

The authors conclude that a wide range of issues have been examined relating to the impact of stroke on individuals and caregivers, including patient and family experiences of acute care, the quality of information available about stroke, motivation for and expectations of recovery and rehabilitation. Additionally, qualitative studies addressing the longer term impact of stroke have identified loss and uncertainty as major emotional factors stroke survivors face. The organisation and delivery of services has also been addressed within the qualitative literature, for example the experiences of staff working with stroke survivors and their families regarding barriers to providing care, including expressive language difficulties and emotional factors. However, they suggest that future studies should relate back to the delivery of best-quality stroke care. To do so, they suggest the use of meta-analysis methodology and an increased collaboration between researchers, service

users and service providers in developing research questions and new research strategies. Furthermore, they suggest specific issues which would benefit from future qualitative research, for example, regarding the exploration of processes leading to delays in presentation and admission at the onset of stroke, secondary prevention strategies and research towards longer term care which better meets the problems identified by stroke patients and their families (McKevitt *et al.*, 2004).

There are, however, a number of limitations to this review. The EUSI guidelines against which the studies were mapped are derived from the clinical expertise gained from the published research evidence itself. Such an approach may have led to bias within the review and prevented gaps in the literature being identified. Further, the description of inclusion and exclusion criteria for papers included in the McKevitt *et al.* (2004) review was limited. It appears that papers that were “consistent with the valid aims of qualitative research” were included (McKevitt *et al.*, 2004, pp1500). This is defined as being when the aim of the qualitative research is to “understand social processes and behaviours (...) in natural rather than experimental settings, and from the perspective of participants” (McKevitt *et al.*, 2004, pp1499). As a result a large number of papers were included with little discussion of their quality, and the findings are descriptive, almost in list form, which makes it difficult to pool the findings.

Salter *et al.* (2008) have taken a further step towards pooling the existing research and carried out a qualitative meta-synthesis looking at the experience of living with stroke. Nine robust qualitative studies were included, with themes and supporting interpretations compiled and reviewed independently to identify recurring themes. This review identified an overarching dominant theme of “*change, transition and transformation*” whereby survivors experienced stroke as a sudden and catastrophic life event which led to a profound disruption to everyday life which required the reinterpretation of the self. They identified four additional overlapping themes: “*Loss*” of independence, confidence, control and ability; “*uncertainty*” about what the future might hold; “*social isolation*” and withdrawal as survivors feel distanced from others, within the context of the importance of relationships for support, comfort and encouragement; and “*adaptation and reconciliation*” as survivors

develop resilience and begin to focus on more positive aspects of their lives as they adapt to the changes brought about by stroke (Salter *et al.*, 2008, pp597). This study not only pools the existing published research, but adds an additional layer of analysis and interpretation. The authors describe their methodology as a form of triangulation, promoting trustworthiness and enhancing comprehensiveness through the use of multiple sources, methods, researchers and theories. The process of qualitative meta-synthesis is a relatively recent development and as such there are no guidelines on the appropriate selection of studies to be included in such a review. Salter *et al.* (2008) have, however, explicitly stated and justified their broad inclusion criteria and methodology. As is so often the case, one criticism, also identified by the authors, is that the studies included in the synthesis excluded those with significant cognitive or language impairment post stroke.

Qualitative research has enabled an understanding of the experience of living with stroke to begin to develop. This knowledge combined with what is known about the functional impact and recovery enable services to provide more effective and meaningful care for stroke survivors. However, a number of aspects of the experience of life after stroke have not been addressed and questions remain unanswered. McKeivitt *et al.* (2004) state that further research is required to improve longer term care which better meets the problems identified by stroke patients and their families. Salter *et al.* (2008) state that the delivery of services should have a focus on the intervention recipient rather than the service provider or clinical interpretations of recovery. As such, services must reflect the needs and concerns of individuals by “taking the time to discover the personal narrative and stories of patients (Salter *et al.*, 2008, pp601). One way to act on these recommendations for future research is to examine the narratives of stroke survivors to discover how they make sense of their lives after stroke which may help to inform how these services can be both designed and individually tailored.

## **1.5 Impact of Stroke on Ageing**

There are a multitude of theories of lifespan development and ageing. However, there is currently little understanding of the impact of stroke in relation to normal ageing processes. The theories that have guided the design, analysis and interpretation of this study are outlined here.

### **1.5.1 Psychosocial theories of ageing**

#### **1.5.1.1 *Disengagement, activity and continuity***

Cumming and Henry (1961) described disengagement theory, which postulates that impending death stimulates a mutual psychological withdrawal between the older person and society. Gender differences are highlighted due to the traditional gender roles within Western societies of men playing more instrumental roles while women's tend to be more socioemotional. In contrast to this, Activity Theory (Havighurst, 1953) suggests that inactivity is a societally induced problem stemming from social norms. Indeed there is evidence that more active older people are more likely to have higher levels of life satisfaction (Coleman, 1999).

In the 1960s debate raged regarding these two theories, focussing on the difficulties teasing apart general age changes and generational changes that exist as younger cohort norms begin to dominate society and societal expectations. Disengagement Theory received much criticism as it was derived from overly generalised findings using a small sample, and further evidence suggested that disengagement in old age is closely linked with isolation earlier in life rather than ageing *per se*. However, there also appeared to be evidence of observable voluntary disengagement, which was insufficiently explained by both of these theories (Coleman, 1999).

It seemed that the process of ageing was better captured by focussing on the role of continuity of different types of lifestyle over age. However, no single model of social and psychological ageing was developed (Coleman, 1999).

Atchley (1989) described the Continuity Theory of Normal Ageing which takes a lifespan perspective, challenging Disengagement Theory while building on Activity

Theory. It is postulated that older adults strive to maintain their lifestyles by adapting strategies they have used previously. These adaptations enable activities and relationships to continue despite age related changes, striving for equilibrium between individual and society and maintaining wellbeing. However, Continuity Theory is also not without criticism. Normal ageing is assumed to describe ageing without long term illnesses, and it is argued that insufficient attention is paid to the impact of societal pressures on ageing (Quadagno, 2007).

#### **1.5.1.2      *Learned helplessness and dependency***

Other theories attempt to examine the interplay between society and ageing. The Model of Learned Helplessness (Seligman, 1975) describes dependency as a response to loss, resulting from a perceived absence of control over outcome. Learned Helplessness refers to the tendency for individuals exposed to multiple unforeseen adverse situations to develop a sense of helplessness whereby they seem to perform less well than their physical and mental abilities would suggest they are capable of (Coleman, 1999). This relates closely to the excess disability discussed in section 1.3.2., whereby the impact of illnesses such as stroke is magnified by other factors, such as depression (Laidlaw, 2008).

Related to this, the Model of Learned Dependency (Baltes, 1996) describes old age as a consequence of societal conditions rather than a consequence of ageing and decline. Dependency in old age is suggested to occur as a result of various social processes including reinforcement for dependency and neglect or punishment in response to the pursuit of independence (Coleman, 1999).

These theories offer insights into the difficulties currently encountered within health and social care systems as attempts are being made to shift from traditional models designed to react to acute illnesses towards models where enablement and self management are paramount. This requires a cultural shift in expectation and power balance, along with individual shifts away from dependency and helplessness.

## **1.5.2 Developmental theories of ageing**

### **1.5.2.1 Erikson's theory of psychosocial development<sup>1</sup>**

Erikson's (1963, 1986, 1998) theory of psychosocial development describes the self forming in adolescence and early adulthood with transformations in mid and late life (Coleman, 1999). This theory highlights the problems and developmental tasks that present at the different stages of life, as well as the strategies, responses and resources used in dealing with these problems (Gleitman *et al.*, 1999).

Erikson describes a series of major crises that are endured by humans throughout the life cycle. At different stages throughout life individuals reach a critical confrontation between the individual identity they have achieved and the demands posed by social and personal situations. Within Erikson's model, old age is viewed within an entire life course perspective. Successful development is achieved through mastery of certain tasks, which are driven by biological pressures combined with social and cultural expectations (Brown & Lewis, 2003). In late adulthood, views of self are related to acceptance of the life that has been lived as the syntonik element, ego integrity, conflicts with the dystonic, despair. Ego integrity relates to the integration of the life lived and subsequent acceptance of it (Coleman, 1999; Erikson *et al.*, 1986). Successful resolution of the eighth stage occurs with acceptance of the past as inevitable and satisfying along with an acceptance of approaching death and results in ego integrity. If life is perceived to have been a failure too late to remedy, the individual will experience despair (Brown & Lewis, 2003).

Erikson originally stated that successful completion of each previous stage is necessary for the development of ego integrity. He later mellowed this assertion to describe normal development requiring positive resolutions to outweigh negatives (Brown & Lewis, 2003). However, Hannah *et al.* (1996) found significant positive correlations with scores of outcome across the eight stages – that is, the degree to

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<sup>1</sup> Erikson's (1986) Theory of Psychosocial Development is illustrated in Appendix 2

which one stage is resolved is closely correlated to that individual's degree of resolution in other stages of their life. They conclude that an individual must experience the previous crises in order to broach the eighth in a meaningful and relevant way (Brown & Lowis, 2003; Hannah *et al.*, 1996).

After his death, Joan Erikson (1998), the wife of Erik Erikson, added a ninth stage to his model to address the challenges of the older old. In Erik Erikson's later years he appeared to have shifted his views, saying that it would not be possible to resolve a lifetime of crises equally well. He also observed that ageing is not predetermined by the life lived previously. Joan Erikson suggests that following successful completion of stage eight, new demands, re-evaluations and difficulties present, whereby the ageing self is truly confronted and continued life satisfaction is possible (Brown & Lowis, 2003). Tornstam's (1989) theory of gero-transcendence is drawn on which suggests a shift in meta-perspective. This shift moves the individual from the rational materialistic stance to a more cosmic and transcendent perspective, which often develops with increased life satisfaction. Tornstam (1989) suggests that wisdom arises out of gero-transcendence.

Whereas Erikson's original model concluded with ego integrity developed through looking back, accepting the life lived and a preparedness for death, Tornstam (1989) describes looking forward and outward. This shift in perspective could be misinterpreted as a negative process of disengagement as individuals look beyond themselves into the future. However, gero-transcendence is seen as a positive withdrawal which often includes a decrease in self-centredness and increase in quiet reflection, moving beyond an acceptance of the inevitability of death to redefine time and space (Brown & Lowis, 2003).

Joan Erikson (1998) suggests that during this quiet reflection, older old individuals may revisit previously unresolved crises. With the frailty and physical decline that often accompanies the 80s and 90s, conflict such as trust and mistrust can be revisited as an individual can no longer trust their ability to maintain independence. Resolution of conflicts throughout the lifespan can be a source of growth and



strength. In the ninth stage, acceptance of the dystonic elements throughout life can lead towards gero-transcendence (Brown & Lowis, 2003).

While Erikson's model offers helpful insights into the tasks of development at different stages in life, there are a number of limitations. These include questioning the model's implied sequential unidirectional linear structure to development and the suggested age ranges (Whitbourne *et al.*, 1992).

### **1.5.3 Successful ageing**

There has been a shift from exploring criteria for successful ageing towards attempts to describe the processes involved in successful ageing (Ouwehand *et al.*, 2007).

#### **1.5.3.1 Future time perspective**

Carstensen (1993) discusses time perspective in relation to ageing. According to Carstensen's (1993) Socio-emotional Selectivity Theory, motivational focus shifts throughout life. Earlier in life, knowledge-related goals aim at knowledge acquisition, career planning, development of social relationships and investments that will pay off in the future. Later in life goals are more emotion-related and aim to maintain emotional balance, such as pursuing emotionally gratifying interactions and activities whose benefits can be realised in the present. The observed reduction in social network participation in older people is motivated by a redistribution of resources rather than a reaction to social contexts (Carstensen, 1993).

Carstensen's (1993) theory posits that these goal shifts are age-associated changes in time perspective rather than ageing alone, for example this has been demonstrated in studies involving people with HIV (Carstensen & Fredrickson, 1998). When the future is seen as open ended people tend to focus on future-oriented/ knowledge-related goals. When time is felt to be running out, focus tends to shift towards present-oriented/emotion-related goals (Carstensen, 1993).

Further evidence of this theory was shown by a qualitative longitudinal study exploring the experiences of older people at age 85 and again at age 92. It was also found in this study that the older old had a reduction in time perspective so the

emphasis was on present day. The participants also revealed use of cognitive strategies of adjustment, such as taking each day at a time and losing interest in those activities which were no longer functionally possible (Argen, 1998).

### **1.5.3.2      *Selective optimisation & compensation***

Selection Theories mediate between those of activity and disengagement. These theories highlight the beneficial effects of becoming more active in some aspects of life, while disengaging from others (Coleman, 1999).

Baltes and Baltes (1990) advocate a theory which highlights the psychological gains as well as the losses at various life stages. There are greater losses in old age compared with other life stages. However, this theory describes how many successfully cope with the challenges of ageing by applying the principles of Selection, Optimisation and Compensation (SOC). *Selection* is whereby the most important tasks and activities which suit individual skills and situations and give life meaning are prioritised. As a result others are de-prioritised as realistic goals are set. *Optimisation* describes how the best conditions are created to enable completion of these tasks, using strengths and resources to maintain high levels of function in some selected areas. Substitute skills and strategies are developed as *compensation* for any disability, enabling tasks to be achieved in different ways. Such compensation strategies may include mental strategies, such as pacing, or the use of aids, for example, a walker to support mobility or a computer to support memory.

Baltes and Baltes (1990) draw attention to the dilemma that such approaches to understanding successful adaptation to the challenges of ageing rely purely on subjective views. As such, reality may be distorted or denied, leading to the over or underestimation of the extent of the hardships faced (Coleman, 1999). While it is helpful to examine the objective situation an individual finds themselves in alongside the perceived experience, this highlights the importance of the story that people tell themselves and others to understand the impact of various situations.

Ouwehand *et al.* (2007) propose that SOC is only one aspect of the complex process of successful ageing. They suggest that while SOC offers a useful description of

dealing with ego associated losses, alternative strategies seem to be helpful in preventing potential threats to goals, such as proactive coping. They suggest that proactive coping may lead to prolonged availability of resources necessary for optimisation and compensation and so delay disengagement from valued goals (Ouweland *et al.*, 2007).

### **1.5.3.3 Self conception through the life course (McAdams, 1990)**

Recent theories on development and ageing have taken a broader approach extending beyond life satisfaction and functional adaptations by looking more closely at narrative. As discussed in section 1.5, the use of language enables us to construct narratives, or self stories which are told to ourselves and others, set on a cultural stage. This approach has led to new ways of exploring the experience of ageing and the continuity and changes that arise with age.

McAdams (2001) integrates life story literature with that on socio-emotional selectivity theory and time perspective. He proposes a life story model of identity, which describes unity and purpose being achieved through the construction of internalised and evolving narratives of the self. This life story model bridges themes in developmental, cognitive, personality and cultural psychology (McAdams, 2001) and highlights the usefulness of applying a narrative/life story framework to understanding individuals' experiences.

Numerous researchers have suggested that the life story becomes more coherent with age (e.g. McAdams, 1993; Riessman, 1993). In childhood and adolescence, expectations of the future are formed, while a story begins to be constructed of the lived experience of life (Coleman, 1999). As an awareness of mortality increases in mid-life, this story begins to consolidate. McAdams (1990) related this to Erikson's generativity, suggesting that generativity requires a sense of who the individual is, their past and their future.

Events that are not consistent with the life story require adaptation. This seems to take the form of elaborating the life story in order to intertwine the new experiences and scenarios. This process has been discussed in the form of life review and

reminiscence (Butler, 1963). Such processes enable a life story to find and maintain meaning through links with the past. This at times entails transforming present experiences, for example, by identifying themes throughout life meaning can prevail despite the objective reality changing. Continuity is also boosted by making the past vivid, for example through stories which emphasise the important people, relationships or events (Coleman, 1999).

As these stories are influenced by social norms, changes in society can interrupt this process. Furthermore, stories require an audience to tell the story to, which can be missing in the lives of many older people living in social and emotional isolation from others. Life stories also require a sense of agency and of having lived a life, rather than featuring as an object in an account of what has happened to them (Coleman, 1999).

#### **1.5.4 Stroke and ageing**

Illnesses, such as stroke, can interrupt the continuity of life, limit independence, depersonalise the social environment, alter reference groups and limit the use of previous coping methods (Broomfield *et al.*, 2010). Often the characteristics that are most highly valued in Western cultures, such as competence, independence and usefulness are reduced following stroke. In addition, the social situations in which positive interpersonal characteristics are exercised, such as humour and warmth, are often limited by the functional effects of stroke.

Kauffman (1988) describes sudden and unexpected illnesses, such as stroke, as likely to rouse autobiographical work whereby the past life and future goals are questioned (Coleman, 1999). It is not the continuity *per se* that is important, but rather the integration of such changes into the life story in order to achieve meaning throughout life.

#### **1.5.5 Summary of the impact of stroke on ageing**

Ageing and lifespan development are diverse processes and attempts to capture and explain them have resulted in many theories. Various approaches have examined the social and individual forces that occur in ageing, from engagement or disengagement

to integrity, transcendence and life story coherence. However, illnesses such as stroke have a sudden impact on these normal and gradual ageing processes. It is not yet clear what psychological manoeuvres are implemented at such times of change and loss to attempt to maintain coherence within the life story and identity.

## 1.6 Narrative

The narrative, or story we tell ourselves and others about an event can allow us to deal with and explain exceptional occurrences and to make them more manageable (Hjelmblink & Holmstrom 2006).

*We are all tellers of tales. We each seek to provide our scattered and often confusing experiences with a sense of coherence by arranging the episodes of our lives into stories.”*

McAdams (1985) as cited in Murray (2008, pp113)

Examining the narratives told by individuals about unexpected events can offer insights into the complexities and contradictions within the experiences of growing older, and how individuals make sense of their experiences in terms of ongoing development, or ageing (Phoenix *et al.*, 2010).

### 1.6.1 Biographical disruption

One aspect of the stroke survivor's recovery which has been revealed in narratives is coping with a disrupted autobiography and the anxiety arising from an uncertain future. Professionals, family and friends also share this uncertainty. Bury (1982) discusses “biographical disruption” occurring as an interruption in someone's life story. For example, a stroke alters the expected course of an individual's life, and redefines their future.

More recent research suggests that the impact of stroke is not so straight forward. The Sociologist Pandora Pound discusses biographical disruption in stroke. She observed through narrative analysis that a group of stroke survivors in the East End of London did not perceive their stroke as a biographical disruption, but rather a biographical continuation of the tough lives they had lived. This was interpreted within a sociological framework as reflective of the stoicism this particular population are known for. Pound *et al.* (1998) suggest that this may be generalisable to other older people who have had a stroke, and query the applicability of “biographical disruption” in older people who experience stroke.

Nonetheless, the evidence relating to biographical disruption in stroke is mixed. Hinojosa, *et al.* (2008) conducted research with a group of veterans one month post stroke and found indicators within their narratives that stroke had acted as a biographical disruption, and disrupted their expectations for ageing and their religious beliefs (Hinojosa, *et al.*, 2008). Becker and Kaufman (1995) looked at stroke survivors narratives around uncertain illness trajectories, and compared these with those of physicians. They found that stroke survivors' narratives contained many concerns about the future, but focussed on recovery, bound within hope and agency. Individual effort and determination were viewed as crucial for recovery success (Becker & Kaufman, 1995). Williams (2000) reviewed the biographical disruption literature, concluding that it remains unclear as to how biographical disruption themes fit with other aspects of recovery or normal ageing.

### **1.6.2 Time perspective**

As discussed, viewing disease as disruptive to a person's life rather than a physiological event opens up the ability to begin to understand the psychological impact of stroke and how patients recover (Hjelmblink & Holmstrom, 2006). A study by Hjelmblink and Holmstrom (2006) explored the perception of time in stroke survivors. Participants were asked to talk about their present life and their conceptions of future life. Narratives that referred to temporal aspects were thematically analysed with reference to narrative time models. The authors discuss the patients' moving from the knowledge that they were mortal to a deeper understanding that they are vulnerable and temporal, which created a temporal split between 'before' and 'after' their stroke on their autobiographical time line. This required them to revise their imagination of the future as they were no longer able to construct a narrative about their future on an infinite temporal line. They found that stroke patients handled an uncertain future by using temporal models in their narratives, for example a cyclical model of the day-to-day routines that are repeated from week to week provides confidence in their near future and predictability to everyday life. The authors suggest that professionals should support stroke patients by reinforcing these models (Hjelmblink & Holmstrom, 2006).

As discussed previously, Carstensen (1993) describes a change in future time perspective resulting from age-associated changes, such as illness. This appears to lead to a shift from future-oriented goals relating to knowledge acquisition towards present-oriented goals with greater emotional focus.

Faircloth *et al.* (2004) also looked at stroke survivors' time perspective by examining the vocabulary of biographical work. As part of a mixed methods study, they analysed the narratives of 111 male US Veterans who had survived stroke at one, six and twelve months post stroke. The average age of their sample was 67 years and 70 per cent of participants were still working outside the home. They came from Puerto Rican Hispanic, African American and non-Hispanic White backgrounds. The researchers were interested in the ordinary resources used in narrative productions of the future in the context of stroke survivors. The ordinary resources used in their constructions included God and spirituality (in terms of trust in God to determine future), co-morbidities, and activity and leisure. Almost all of their participants had at least one co-morbidity (97 per cent had one co-morbidity; 90 per cent had two). They found that in comparison with the difficulties posed by some co-morbidities, stroke was relatively insignificant, despite a relatively young sample. In terms of activity and leisure, a positive future was articulated through activity, viewing stroke as a "*wake up call*" which provided the impetus to make good use of time. They also noticed a number of false ideas about stroke and other illnesses in the narratives, suggesting a lack of congruence between the current knowledge among professionals and patients themselves (Faircloth *et al.*, 2004).

Whilst interesting, there are a number of limitations in this study. The authors aimed to relate their findings to normal ageing processes. They did not report the range of ages included, however the mean age is 67 and a number of participants quoted are in their late fifties. This study does not appear to have examined the older old population. A further criticism of this study, drawing on Yardley's (2000) guidelines is the lack of transparency regarding the researcher's influence and the process of analysis. Further, conclusions are drawn regarding the impact on functional rehabilitation services, with no reference to poor mental health or psychological adjustment.



### **1.6.3 Redemption sequences**

McAdams (1999) looked at narratives of those who have experienced significant trauma and identified “redemption sequences” as particular narrative forms that appear in some accounts of significant scenes in a person’s life story. In redemption sequences an emotionally negative event or circumstance leads to an emotionally positive outcome – the original negative state is “redeemed” or salvaged by the good that follows it. Interviewing a wide range of participants, McAdams has explored life story high points, low points and turning points as well as times of significance, decision or moral dilemma to explore how people adjust to life events (McAdams, 2001). Stroke as a traumatic or significant event has not yet been examined in this way.

### **1.6.4 Summary of narrative**

The narrative, or story we tell ourselves and others about an event or period of time, can allow us to deal with and explain mismatches between the exceptional and the ordinary. Narratives allow us to re-cast chaotic experiences into stories in order to make sense of them and to make them more manageable (Hjelmblink & Holmstrom 2006). While there is a wealth of qualitative research examining the impact of stroke, narrative studies have not as yet explored the complex adjustment following stroke. Examining narratives may offer some insight into why some people who have a stroke adapt well while others do not.

## **1.7 Aims of Study**

Stroke often results in great change in people's lives. This change can occur functionally, socially, psychologically and spiritually. While much is known about the physiological mechanisms of stroke and the resulting functional impact, little is known as yet about how stroke survivors make sense of their experiences and regain a sense of coherence in their lives and how this relates to theories of ageing. It seems that employing narrative analysis may offer new insights into this process.

This study aimed to explore the narratives of a group stroke survivors in the over 65 population of Fife to examine how they made sense of their lives following stroke.

The overall aim was to add to the existing understanding of the impact and meaning of stroke and how stroke patients adjust and adapt to their situation within the context of lifelong development and ageing. It was hoped that such understanding of how people adjust well to stroke may inform how rehabilitation services can support those who do not in order to promote wellbeing and maximise potential, limiting the emotional, financial and time costs of excess disability.

### **1.7.1 Principle research objective**

To conduct an analysis of the narratives of stroke survivors to examine how they found meaning and made sense of their lives after stroke.

### **1.7.2 Secondary research objective**

To make reasonable adjustments in order to include at least one participant in this study who has expressive language impairment as a result of stroke.

## **2 METHODOLOGY**

### **2.1 Chapter Summary**

This chapter explains the research approach adopted in this study. This involves examination of the theoretical assumptions of the methodology as well as a detailed description of the method used to collect and analyse the data. The research setting and context are also described. Participants are introduced in Chapter 3. The measures taken to ensure quality are outlined and ethical considerations are explored.

## 2.2 Design

This study used qualitative methodology. Qualitative methodologies are concerned with exploration and description of individuals' personal and social experiences, aiming to provide rich descriptive accounts of the matter being researched (Smith, 2008). This differs from quantitative research methods which are concerned with measurement and statistical analysis, for example counting occurrences or the size of associations between entities. In qualitative research, data often takes the form of natural verbal accounts, although written material can also be used. Transcripts of this material are analysed to enable interpretation of its meaning (Smith, 2008).

The aim of this study was to examine how individuals found meaning and made sense of their lives after stroke. Fauconnier (1994) said "*language does not carry meaning, it guides it*". Sense is made linguistically, and so this aim was most suitably approached through qualitative methodology in order to address each individual participant's experience.

There are various qualitative methodologies which are underpinned by different, although sometimes overlapping, theoretical assumptions and methodological emphases (Smith, 2008). As outlined in Chapter 1, narrative methodology has been used in various studies to examine how individuals make sense of unexpected events. While there is an array of qualitative studies looking at the impact of stroke, none have as yet looked at the narratives of older stroke survivors in Scotland to examine how they make sense of their experiences in relation to their ageing. Narrative methodology was therefore selected as the most suitable means of addressing the research question.

### 2.2.1 Narrative methodology

Narrative analysis is currently used as an umbrella term to describe various approaches (Elliot, 2005). There is no single definition or procedure of narrative analysis. The word narrative is derived from the Latin verb *narrare* which means to recount, and is related to the adjective *gnarus* which is translated as 'knowing' (Phoenix *et al.*, 2010). The term 'narrative' is used in this context as a story that a

person tells to give external expression to internal representations of events, thoughts and feelings (Squire *et al.*, 2008). This is different to an account or sequence of factual events. Rather, it involves a story with a point to it, with characters embedded within in it, set within a cultural context. The story has a plot connecting events that unfold sequentially over time, connecting events in a meaningful way to offer explanations about a person's experiences (Phoenix *et al.*, 2010). Experiences are organised through narratives and assigned meaning by storytelling. Narratives are social devices that require an audience. The audience may be the narrator themselves, or those external to the narrator. The presence of the audience influences the very construction of the narrative itself as it is accepted, challenged or silenced (Squire *et al.*, 2008). Riessman and Speedy (2007) state that "*events are selected, organised, connected and evaluated as meaningful for a particular audience*" (Riessman & Speedy, 2007, pp430).

This co-construction is demonstrated by participant 5<sup>2</sup>:

Participant 5: *"It was found that I had blood floating about in the back of my head. I had, >take you back a bit< I'd had headaches at the back of my head ... What was the name of it? You know what it was, I think you mentioned, sub something?"*

Me: *"Was it subdural stroke?"*

Participant 5: *"Yeah, something like that."*

Me: *"Right, so it was bleeding sort of outside the brain?"*

Participant 5: *"That's right it wasn't in the brain it was outside the brain."*

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<sup>2</sup> See Appendix 6 for transcription notation.

### 2.2.2 Theoretical underpinnings

There are two theoretical antecedents to current narrative research methodology – humanist (e.g. Bruner, 1990) and post-structuralist (e.g. Todorov, 1990) traditions (Squire *et al.*, 2008). These approaches oppose positivist empiricism by taking holistic, person centred approaches, making sense of the world using reason and experience. The focus is on story structure and content, welcoming narrative fluidity, contradiction, both conscious and unconscious meanings and the power relations of day to day life. It is assumed that narratives are produced and understood in the context of multiple subjective perspectives embedded within the social construction of language rather than single storyteller and hearer agents (Squire *et al.*, 2008).

Narrative inquiry does not aim to draw conclusions of certainty, and as such there are a broad range of approaches within narrative research enabling the researcher to engage with their data (Elliot, 2005). There are common assumptions across these approaches. One being rather than aiming to objectively describe experience, narrative analysis entails gathering biographical accounts which perform social actions, and exploring how order is imposed on the experiences to make sense of events and actions within personal, interpersonal and cultural contexts (Phoenix *et al.*, 2010).

Phoenix *et al.* (2010) draw these together within the context of ageing research and produce a typology of the different ways to do narrative analysis. They suggest that there are two broad sub types of narrative analysis, although they are considered to fall on a continuum. *Story analysts* view analysis as a systematic task while *storytellers* approach analysis as a form of writing. The latter collect, invite and generate stories, but the analysis is the story, which is in itself both analytic and theoretical. This offers a high degree of engagement with the stories beyond telling how stories are used. Storytellers often produce written, oral or theatrical performances aiming to show rather than to tell the story (Phoenix *et al.*, 2010).

This study commits to a story analytic technique, which also collects, invites and generates stories, but then conducts an analysis *of* them. The stories produced during

interview are treated as data which are analysed systematically and rigorously. This requires me to both immerse myself in the data, while also stepping back from the stories in order to apply analytic procedures and develop theoretical abstractions (Phoenix *et al.*, 2010).

Within the story analytic approaches there are various techniques. These focus on different layers of the story, from the contextual factors (*wheres* and *whens*) to *what* is said to *how* it is told (Holstein & Gubrium, 2004). The *whats* explore the substance, structure and plot, while the *hows* look at the way in which the story unfolds.

*“Advocating one kind of analysis over another seems less productive than asking how we might fruitfully combine different forms of analysis in order to explore the ‘whats’ and ‘hows’ of narrative and generate different more complex understandings of ageing”*

(Phoenix *et al.*, 2010, pp9)

This study therefore takes a mixed approach to enable different layers of analysis to look at the *wheres*, *whens*, *whats* and *hows*.

Another broad divide within narrative research is whether the focus is on event or experience narratives. Labov and Waletzky (1967) describe ‘*event narratives*’ which focus on the spoken recount of a particular event that happened to the narrator which is mostly constant – such as the event of having a stroke. ‘*Experience narratives*’ on the other hand describe a general or imagined phenomenon or things that have happened to the narrator, which vary over time and across circumstances of life, often producing different stories depending on the time and audience (Squire *et al.*, 2008). Narrative accounts can therefore represent internal states, or external social circumstances. This study is concerned with the experience of life after stroke and will therefore focus on *experience narratives*.

This study is particularly interested in the thoughts and feelings of the narrator, and the meaning they attach to their story. However, the audience shapes the story told

and how the story is heard and this co-construction of narratives must not be overlooked:

*“A speaker’s intent is met with the analyst’s interpretation, which in turn is situated in shifting discourses, history, politics and culture. It is never ending, always open to re-interpretation”.*

Riessman, 2008 (in Salmon & Riessman, 2008, pp83)

As such, an awareness of the role and impact of the audience (me) on the story produced is also taken into account during analysis.



## **2.3 Participants**

### **2.3.1 Number of participants**

Qualitative approaches usually aim to understand a relatively small number of participants' views. Narrative research aims to explore a range of views rather than to represent a population. Existing narrative research has utilised sample sizes ranging from 2 participants (for example, Gray *et al.*, 2005) to over 20 participants (for example, Yaskowich & Stam, 2003). When working with large amounts of data from each participant, Morse (2000) suggests that six to ten participants is sufficient.

Clinical Psychology doctoral theses are constrained by time as there are significant additional clinical demands on the researchers. Dallos and Vetere (2005) recommend small samples in such time limited projects. They suggest a sample size of five (plus or minus two) in order to retain an idiographic focus.

After close reference to guidelines on clinical doctoral theses and the recommendations of published literature, this study aimed to recruit four to six participants who collectively represented a range of views. Discussion with the Chest Heart & Stroke Scotland (CHSS) nurse manager revealed that approximately 25 patients were discharged throughout Fife each month, which would be approximately 150 during the recruitment window of October 2009 to March 2010. Of these, it was estimated that 60 would meet the inclusion criteria and 15-20 would agree to participate. Following advice from the Research Ethics Committee, it was agreed that invitations would be sent in small batches to minimise the number of people who would be contacted but not included.

Seven participants opted in to the study from the first mail drop (sent to 35 people). Six of these participants met the inclusion criteria and offered a range of characteristics (five participants had ischaemic strokes while one had a haemorrhagic stroke). As this satisfied sufficiency, no further invitations were mailed. This decision was reinforced by staffing shortages within the CHSS nursing team meaning that they were unwilling to send further invitations within the time window necessary.

One person who opted in did not meet the inclusion criteria. I suspected cognitive impairment and she appeared to have little insight into these cognitive difficulties. Furthermore she also fell below the lower age bounds. I thanked her for her interest and time and explained that she did not quite meet the criteria for this study due to her age and some of the difficulties she discussed. She reported being happy with this and had no further questions or feedback about the procedure.

### **2.3.2 Selection of participants**

Due to the ethical constraints of accessing this population, convenience sampling was employed. This entailed identifying the population of interest, developing strict inclusion and exclusion criteria and accepting those who responded to invitation (Cohen & Crabtree, 2006).

Suitability was primarily evaluated using the inclusion/exclusion criteria described in the next sections. However, a range of additional characteristics were sought to ensure a variety of perspectives were available offering both depth and breadth of views.

The main characteristics the study aimed to sample included:

- Male and female participants.
- A range of ages within the Over 65 population.
- Participants who have had one stroke and those who have had more than one.
- Participants who have care support and those who do not.
- Participants who live alone and those who live with someone.
- Participants who have expressive language difficulties and those who do not.

The first six suitable participants who opted in were included and further recruitment via mailing recruitment packs ceased. This strategy had two advantages. Firstly, it minimised the number of people contacted but not selected. Secondly, as sampling was not wholly deliberate (I did not examine all potential participants meeting inclusion criteria and select which to include), some degree of randomness was achieved, which increases credibility of the small sample (Blankertz, 1998; Cohen & Crabtree, 2006).

### **2.3.3 Inclusion criteria**

Participants had to be over the age of 65 and experienced stroke in the last 12-24 months. This allowed for at least one year to have passed since discharge from hospital following a stroke, during which time rehabilitation was likely to have reached its maximum potential and medication would be stabilised.

Initially, it was planned to exclude participants who had another stroke within the past year. However, as recurrence of stroke is a common experience in this population, this was later amended to allow the inclusion of one participant who had a further stroke within the past 12 months so long as the first one was at least one year prior to interview. Two other participants had also experienced more than one stroke, but their most recent stroke was more than a year ago.

Participants were also required to be living in their own home or sheltered accommodation in the community.

Participants were required to be cognitively able to consent and understand the questions asked, and to be physically able to provide verbal or written responses.

### **2.3.4 Exclusion criteria**

Participants were excluded if they had significant cognitive impairment impacting on ability to consent to participation in research. CHSS nurses initially determined cognitive suitability using their clinical knowledge and the inclusion criteria. I further assessed cognitive suitability as is explained in section 2.5.

## 2.4 Interviewing

Data was collected through individual recorded episodic interviews. All interviews were conducted by myself. I carried out practice interviews with a colleague and a lay person prior to commencement of this stage of the study.

Narrative research often uses narrative interviewing to elicit data for analysis. Narrative interviewing invites the participant to tell their story right through, with minimal prompting and follow-up from the interviewer (Murray, 2008). In this study, this technique was unsuitable due to the characteristics of the population being interviewed as many stroke survivors have some degree of cognitive impairment, which may impact on ability to sustain attention.

Instead, it was decided that episodic interviewing would enable me to facilitate the participant in telling their story. Episodic interviewing encourages participants to tell their story of a particular experience, providing time and opportunity to share experiences. The interviewer provides focus but also latitude for the participant to develop their own story (Murray, 2008). In this study, this entailed interviewing around the specific episode of the participant's stroke and the time following it until the present day. The interview schedule (see appendix 5) was developed with close reference to Flick's (1997) guidelines, although the language was amended for a Scottish population. My role was to show interest in the participant's narrative account, while presenting a neutral stance so as not to encourage a particular narrative. Here I drew on active listening skills developed initially through COSCA (Counselling and Psychotherapy in Scotland) Counselling Skills Courses and consolidated in clinical training and practice. Interview probes were used to help the participant tell their story, to clarify that I had understood and to encourage the participant to anchor their account within stories of events rather than a factual account. I gave encouraging nods and remarks and obtained clarification by asking questions such as "*Why do you think that is the case?*" or "*Could you give an example of that?*" (Murray, 2008). Narratives are constructed within a social context, and the audience plays a key role in this construction. Regardless of the

nature of interview, analysis must be conducted with this co-construction in mind (Murray, 2008).

## **2.5 Ethical Considerations**

Conducting research with stroke survivors is surrounded by a multitude of ethical quandaries. Advice was sought from academic and clinical supervisors, CHSS, the Research and Development Department within NHS Fife, as well as consulting previous publications and gaining approval from the West of Scotland Research Ethics Committee<sup>3</sup>.

### **2.5.1 Recruitment**

As the study sought to explore the experiences of stroke survivors at least a year after having a stroke, identifying potential participants was problematic. Examining admission records in stroke wards would provide details of strokes within the appropriate time frame, but would offer no indication as to their current situation and whether it would be appropriate to broach participation in research. They may have since died, had another stroke, fallen ill to another condition, or have been left functionally unable to participate. Additionally, there are ethical concerns about a researcher accessing such information.

CHSS nurses follow all NHS Fife stroke patients up at home after discharge. An allocated CHSS nurse visits each patient up to 4 times at their own home throughout the 12 months following their discharge. These nurses would be familiar with their patients' situations and would be able to advise who may be appropriate for inclusion.

However, this mechanism of recruitment posed further ethical concerns. Participation in research must be voluntary and recruitment should ensure that potential participants are not coerced to take part (Dench *et al.*, 2004). A care provider suggesting participation in a research project at the point of discharge may

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<sup>3</sup> Letter of confirmation of ethical approval is provided in Appendix 1

increase likelihood of patients ‘volunteering’, either through a desire to please or in hope of gaining further input.

To overcome these concerns, recruitment packs<sup>4</sup> (containing a covering letter, participation information and opt-in slips) were sent to CHSS Nurses in sealed stamped envelopes. The nurses then identified suitable discharged participants from their database using the inclusion/exclusion criteria. They attached address labels and mailed them to the potential participants. Those receiving these packs were encouraged to discuss participation with family and friends and to take their time thinking about the decision. Those wishing to find out more or to opt-in were asked to telephone me or complete and return an opt-in slip, thereby providing those approached with the opportunity to make a balanced decision regarding participation.

Due to the nature of this sampling it was possible that more participants would opt-in than were required for the study. It was explained in the participant information and at the initial meeting that participants would be selected so that they collectively best provided a range of views using the above criteria. Those not selected would be contacted and thanked for their interest, and the reason for their de-selection would be outlined.

### **2.5.2 Expressive language**

Stroke often results in impairment in expressive language. Such impairments can make this type of research difficult and those affected are often excluded from research studies due to the distress participation may pose (Stroke Association, 2008a; Thomas & Lincoln, 2008). For example, a systematic review of studies that diagnosed depression after stroke found that in 71 per cent patients with aphasia had been excluded (Townend *et al.*, 2007). Bisset *et al.* (1996) highlight the importance of limiting such selection biases and suggest that different methods are necessary to

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<sup>4</sup> See Appendix 3 for Recruitment Pack: Letter of invitation to participants, opt-in slip and Participant Information

obtain the views of the most vulnerable patients in order for studies to be assessed in their true context (Bisset *et al.*, 1996).

The Nursing, Midwifery and Allied Health Professions (NMAHP) Research Unit (2009) state in their Biennial Report that:

*“We endeavour to include where appropriate, a full range of stroke patients including those with aphasia and those who are incapacitated as a result of stroke. In this way we hope our findings are applicable to the wider stroke population that presents in a clinical setting.”*

(Niven, 2009, pp16)

Excluding participants with expressive language impairments limits the ability to gain a psychological understanding of a significant proportion of this population. Therefore, an objective of this study was to attempt to include at least one participant with expressive language difficulties. Colleagues in the Speech and Language Therapy (SALT) Department who were involved in the participants' routine clinical care were available for consultation if required. Furthermore, I had attended a two day training event run by the charity Connect which supports those living with Aphasia. This provided me with information and advice about written and verbal communication with those with language difficulties.

Adjustments were made to accommodate language difficulties depending on the need of the particular participant. Adjustments included the option of writing or typing responses rather than verbally reporting them and providing extra time with additional breaks as necessary. These adjustments were tailored to each participant and the participants and their carers were included in this process. Two participants requested that they did not receive prompts if they struggled to find the correct word, while two requested help with this. Another participant requested a pen and pad of paper beside him to write notes if he was struggling to find words.

### **2.5.3 Cognitive function**

Stroke can result in impairment in cognitive function (Stroke Association, 2008a). For two reasons the presence of significant cognitive impairment was deemed ground

to exclude potential participants from taking part in the study. Firstly, participants were required to give their informed consent to take part, which may not be possible if cognitive impairment limits ability to understand the implications of participation (Simpson, 2009). Secondly, the nature of the data collection required participants to take part in an interview (verbal or written), which may not be possible for those with cognitive impairment. However, there are serious ethical issues about undertaking cognitive assessment for the purpose of research recruitment, such as potential diagnosis (Simpson, 2009). Therefore alternative means of determining suitability were required.

Capacity is multifaceted. Capacity to consent to research participation differs from capacity to consent to treatment, or to make financial decisions (Davies, 2005). Capacity to make decisions about participation in research is defined by the Adults with Incapacity (Scotland) Act 2000 (Scottish Executive, 2000) as the ability to make, communicate, understand and remember decisions. The CHSS nurses screened for cognitive suitability using their patient knowledge and inclusion criteria. This was further explored when I obtained consent.

Resnick *et al.* (2007) suggest using a five item Evaluation to Sign Consent<sup>5</sup> (ESC) form as a method of determining potential participants' ability to consent without carrying out cognitive testing. They argue that this method can appropriately evaluate the capacity to consent to participate in particular research studies (Resnick *et al.*, 2009). This evaluation was adapted for the current study. Participants were considered able to consent if they were able to sustain concentration, communicate with me and demonstrate their understanding by being asked to repeat back the key points of the consent form. The key points examined were:

- There are no risks associated with the study
- Participation involves an interview about their stroke
- They are free to withdraw at anytime
- They can contact myself or their GP if distressed following the interview
- They may not be selected once they opt-in

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<sup>5</sup> See Appendix 4 for the adapted Evaluation to Sign Consent form used



#### **2.5.4 Depression**

Those with severe depression may find participation in research too demanding due to the nature of the symptoms of depression, such as a reduced ability to concentrate and apathy. For such vulnerable individuals participation may be detrimental to their wellbeing or distressing. For this reason, the CHSS nurses were asked to exclude clients who displayed obvious moderate to severe depressive symptomatology, such as enduring low mood, markedly diminished interest in activities, diminished ability to think or concentrate, sleep disturbances, loss of appetite, weight loss or suicidal ideation. The nurses use brief screening tools in their routine care and would be familiar with such symptoms in their clients.

If a participant was displaying depressive symptomatology, or a risk of suicide or harm to themselves or others was identified, I had an ethical imperative to act on this information. At recruitment, potential participants were informed that if I had such concerns, their GP would be notified by telephone on that day where possible, who could make a formal referral to the Psychology Service if appropriate. Participants were also informed that they could initiate this referral themselves if they wished.

#### **2.5.5 Upset during interview**

It was predicted that the interview may illicit upsetting memories for some participants as they recall their experiences and the impact stroke had on their lives. Participants were informed that the purpose of the study would be to explore these issues from the outset. The procedure described in 2.5.4 applied in this situation too, with explicit agreement that the participant's GP would be notified if I was concerned by their degree of upset, or they could initiate this contact if necessary.

#### **2.5.6 Duration of interview**

The interview itself was expected to take 60-90 minutes, although two lasted for two hours. Stroke survivors often experience fatigue and it was possible that some of the participants would find this a long time to concentrate. Participants were given the choice of setting for the interview – in their own home or in a clinic setting to make

them most comfortable. They were offered a short break if required and were able to withdraw participation at any point.

### **2.5.7 Confidentiality**

I only had access to personal data provided by the participants themselves, and have not required access to medical records as what is of interest is the participant's own story rather than a factual account of events. Personal information has been kept in locked filing cabinets within NHS Fife Psychology Department or in password protected electronic form on the secure NHS server, in line with NHS Fife policies regarding confidentiality and data protection and the British Psychological Society's good practice guidelines for the conduct of psychological research within the NHS (Cooper *et al.*, 2005). Audio recordings of the interviews were made on a digital Dictaphone and downloaded onto the secure NHS server. These files have been password protected and labelled with a participant number. Once downloaded, original recordings were deleted from the Dictaphone as per NHS Fife dictation guidelines.

To ensure anonymity and confidentiality of personal data, transcripts were given a participant number so do not contain names or contact details. These files are stored electronically for 5 years on the NHS secure server as per research guidelines (Cooper *et al.*, 2005). Identifiable information in the transcription has been made anonymous where possible without detracting from the richness of the content.

Due to the nature of this research, direct quotations have been used in the dissemination of the findings. A sufficient degree of anonymity has been ensured by removing all obvious descriptors and identifiable information from the extracts used. Participants were informed that descriptive data or direct quotations in an anonymous form would be used in dissemination.

### **2.5.8 Possible risk to me as researcher**

Despite the option being offered of interviews being carried out in a clinic setting, all of interviews took place at participants' homes. This posed a potential risk to me. The NHS Fife lone worker policy was followed to minimise any risk - leaving the

address and time of the appointments with a member of staff in the NHS Fife Psychology Department and arranging to phone that person immediately after each appointment. The appointed colleague would follow the lone worker policy protocol if they did not receive this phone call from me by a given time.

## **2.6 Procedure**

### **2.6.1 Identification of potential participants**

CHSS nurses and their manager reviewed their database to identify potential participants who were been discharged from their service during the 6 month period of October 2009 to March 2010 using the inclusion/exclusion criteria described. This aimed to recruit people who had been discharged from hospital 12-18 months previously, and were likely to have had a stroke between 12 and 24 months prior to recruitment. A design amendment later enabled inclusion of one participant who had a further stroke more recently so as to include his views as this is a common experience in the course of stroke.

After identifying potential participants, CHSS inserted the patients' address labels on stamped and sealed recruitment packs that I had provided containing a covering letter and participant information leaflet.

### **2.6.2 Recruitment**

Potential participants were advised to think about participation and discuss it with their family and friends if they wished. If they then wanted to take part they were required to sign and return a tear-off opt-in form which would invite me to contact them by telephone to answer any questions and arrange a suitable time for an initial appointment. Alternatively they could telephone me to arrange this appointment if they wished. The onus was on participants to initiate contact to opt-in and those who did not opt-in were not contacted again.

At least a week was then allowed before the initial meeting took place to give participants an opportunity to think about participation further and discuss it with family and friends if they wished. It was made clear (in the participant information, consent forms and verbally) that participants could withdraw at anytime without giving an explanation.

At the initial meeting background contextual information was collected so as to determine whether the participant was suitable for inclusion and to gather some information to assist in analysis.

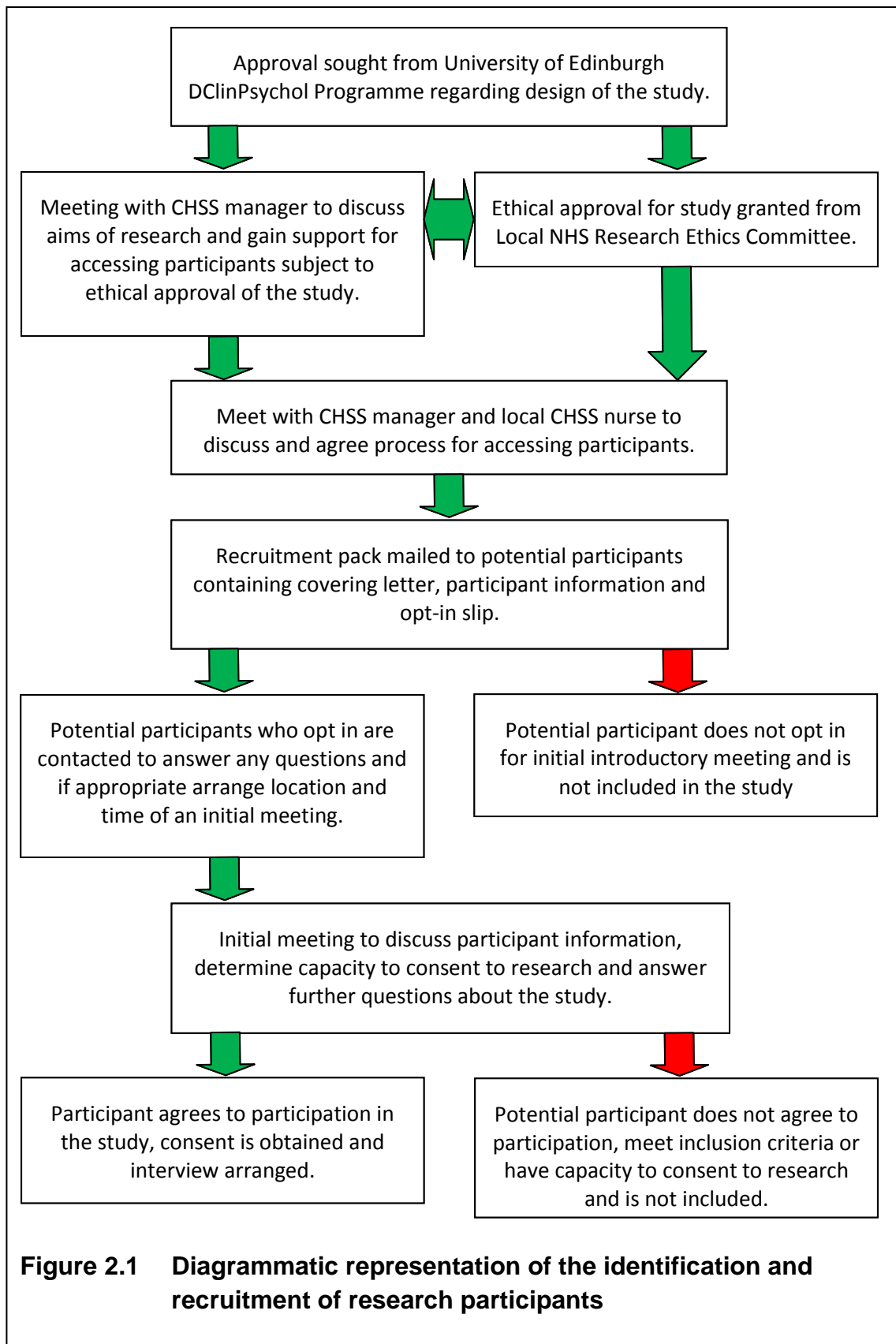
This information related to:

- Stroke history
- Current professional input
- Living situation
- Activities of Daily Living
- Care support
- Other adversities
- Mood (indicators of moderate to severe depression or anxiety)

Due to the nature of sampling, it was possible that more participants would opt-in than were required for the study. The process of selection and de-selection was briefly outlined and an emphasis was placed on communicating that their de-selection would not be due to anything they did or did not do. This procedure was ultimately not required as all those who opted-in and met the criteria were included.

### **2.6.3 Obtaining informed consent**

If the participant met the inclusion criteria and was still interested in taking part, capacity to consent to research was determined using an adapted Evaluation to Sign Consent (ECS) form (adapted from Resnick, *et al.*, 2007) to aid clinical judgement and if appropriate informed consent was obtained. This tool is discussed fully in section 2.5.3.



#### **2.6.4 Data collection**

Suitable participants who were included in the study then took part in a minimally-structured episodic interview at a later date (lasting between 50 minutes and two hours). Participants had the option of this taking place in their own home or in a clinic setting. Further detail on the structure of the interviews is provided in section 2.4 and Appendix 5.

When asked if there was anything that would make him more comfortable during interview, Participant 5 stated that he would like his ex-wife, who remained his close friend, to attend the interview as well. While this changed the audience, she was able to help him construct his story of stroke and reflect on their relationship together. Despite this extra voice, the story told was predominantly of his experiences of stroke, which she helped to co-construct. She rarely mentioned her own perspective on his stroke.

Interviews were audio recorded using an Olympus DS2300 digital recorder.

#### **2.6.5 Duration of participation**

From initial contact participants were actively involved in the study for up to one month. During this time they took part in an initial meeting lasting up to one hour, which was followed at a later date by an interview lasting up to two hours. They were given the opportunity to take short breaks during these interviews if required.

Participants could receive a short written or verbal report of the findings if they wished. Five of the six participants requested a phone call or visit to discuss the findings.

#### **2.6.6 Transcription**

The interviews were transcribed *verbatim* using the ‘Olympus DSS transcription module’ software.

Transcription is regarded as the first phase in the analytic process (Elliott, 2005). It is considered virtually impossible to produce a transcript which captures all of the

meaning communicated when the words were spoken. There are various methods that can be used to organise and transcribe narratives, each capturing different degrees of information. Clean transcripts focus on the content alone, recording only the verbal material while ignoring pauses, intonations and removing repetitions, false starts and non-lexical utterances (*umms* and *errs*). While this is easy to read, it disregards how the narratives are performed. Narrative analysis is concerned with how things are said, as well as what is said (Elliot, 2005; Phoenix *et al.*, 2010). Detailed transcription preserves detail about the way the narrative is recounted. Formal notation systems have been developed by conversation analysts which capture details of pitch, intonation, pauses, rhythm, hesitations, facial expression, body language and so on. This process is extremely time consuming to transcribe and can seem highly artificial to read, which can be detrimental in later stages of analysis (Elliott, 2005).

As such I did not use this more detailed approach, but as a method for preserving sufficient additional meaning conveyed by the speaker, pauses, rhythm, hesitations and body language were recorded<sup>6</sup>. This provides additional information beyond the words alone, whilst creating a written text which is readable.

During transcription, all identifiers were removed to ensure the highest degree of anonymity without detracting from the richness of the data. People and place names were altered to generic descriptors and dates were generalised. For example, (participant's sister) or (local general hospital) were used instead of the actual names stated.

### **2.6.7 Analytic plan**

Many other qualitative approaches, such as grounded theory and Interpretive Phenomenological Analysis (IPA) offer clear frameworks for researchers to follow in data analysis, for example start and end points or the best level at which to study the material, from general to particular (Squire *et al.*, 2008). As described previously,

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<sup>6</sup> See Appendix 6 for transcription notation



there are no such guidelines for narrative analysis (Phoenix *et al.*, 2010; Riessman, 1993). As recommended by Phoenix *et al.* (2010), a range of analytic techniques were employed to explore the complexities of the stories in this study, which entailed different levels of analysis in order to consider the multilayered ways in which stroke survivors understand their situations. The decisions I had to make in selecting the analytic techniques used were closely discussed with my academic supervisor and a qualitative thesis study group. As the coding framework developed and anchor points were identified, I regularly discussed my findings in clinical supervision. This process involved both relating back to the analytic plan to ensure that I was remaining true to the method of narrative analysis as well as ensuring that the analysis was grounded in the data collected. My clinical supervisor also examined the transcripts, coding, memos, restoried narratives and identified anchor points once I had completed analysis as a further step as described more fully in Section 2.7.2.

#### **2.6.7.1 Exploring the whats: Analysis of structure**

Rather than looking at content as other qualitative approaches do, analysis of structure within a narrative analysis looks at the way in which a story is put together (Phoenix *et al.*, 2010). This moves the focus away from narrative content so inhibiting interpretation of the meaning of the narrative from my own theoretical standpoint, thereby facilitating consideration of meaning and what the participant is telling about their experience (Riessman, 1993).

##### *Reading and restorying*

Transcripts were read and re-read to familiarise myself with both the structure and content. I analysed each narrative line by line, paying attention to changes in pitch and speed of speech. Context was carefully considered. This included looking at the *personal* context of the narrator in terms of their life as a whole; the *interpersonal* context thinking about the audience and the co-construction of the narrative; all within the *societal* context which considers the broader social narratives, for example of ageing or of ill-health (Murray, 2008).

Mishler (1986) describes a process of distilling and arranging a story temporally from origins to turning point and conclusion, as a beginning, middle and ending. This is known as restorying. In order to begin to make sense of the narratives I had collected, each narrative was then condensed and re-written in a coherent chronological order to represent the lived experience (Murray, 2008). I used a combination of my own words and those of the participants in this process. Restorying does not aim to capture or produce the truth or reality. These restoried narratives allow participants' voices to be heard in a coherent context, with specific points in mind, framed by my assumptions and those of narrative methodology, (Phoenix *et al.*, 2010). The restoried narratives highlight key issues in the text, identify narrative linkages connecting different parts of the story and identify subplots within the broader narrative. This process inevitably highlights particular features of interest to me as the researcher, such as references to the participant's perspective on ageing. This is therefore not simply imposing a framework or describing the narratives. Rather I 'play' with the account, to-ing and fro-ing remaining open to new ideas and challenges, within the context of the theoretical assumptions guiding analysis (Murray, 2008).

One major assumption I brought into both interview and analysis was recorded in a memo while reading Murray's (2008) chapter on analysis, and appeared in my memos at various times through the analysis:

*Assumption: Stroke was a significant and tragic life event! But what about Pound et al.'s (1998) study looking at the experiences of Eastenders who stoically saw stroke as a 'biographical continuation' of the tough lives they had lived.*

Memo on 22 February 2010

I decided not to share the restoried narratives with participants, as discussed further in section 2.7.2. Member checking (presenting transcripts or restoried narratives to participants) is often used as a process of ensuring quality in qualitative research, as means of checking accuracy of both transcription and interpretation. However,

narratives are fluid. Through telling a story, individuals can move emotionally and cognitively and it is possible that telling the same story at another time, or discussing a summary of the story told, may alter the narrative itself (Phoenix *et al.*, 2010). As mentioned, the role of the researcher also influences the restoried narratives produced (Murray, 2008; Phoenix *et al.*, 2010). This study therefore entailed the co-construction of the narratives at a single point in time (interview) followed by analysis without further input from participants.

### *Focus on form and structure*

This phase examined the structure and organisation of the narratives by looking at the dynamics of plot development, tone and narrative coherence of each participant. In practice, this occurred simultaneously with reading and restorying. This process of analysis is shared with the reader by means of introducing the participants in Chapter 3. Restoried narratives of each participant are presented in appendix 8.

Gergen and Gergen (1984) describe three primary structures of narratives: *Progressive* movement towards a goal; *regressive* movement away from a goal; and *stable* or little change. Robinson (1990) assigned narratives of people with Multiple Sclerosis (MS) into these three broad categories to describe the direction of plot development. Robinson describes *regressive* narratives, whereby the story told of life ending because of the onset of MS; *stable* narratives in which life has changed but is ongoing; and *progressive* narratives whereby the disease had provided new opportunities. McAdams (1993) also focuses on these categories, but uses the tone or emotional flavour to assign them. He describes narratives with a pessimistic tone *regressive*; those with an optimistic tone *progressive*; and narrative with an objective tone *stable*.

Frye (1957) described a different aspect of plot development to describe the narrative turns within a story, using terms commonly applied in literature to describe the genre, or style of narration:

*Comedy* describes a regressive narrative that is transformed into a progressive narrative as values are redefined and positive features of the changed life are

realised; *Romance* describes a progressive story in which the protagonist overcomes adversity and regains what has been lost; *Tragedy* describes a narrative that begins with a progressive struggle, but despite struggle, the narrator is overcome and the narrative becomes regressive; and *Satire* describes a story whereby the protagonist adopts a stable stance and considers the absurdity of life (Murray, 2008).

Gergen and Gergen's (1984) and Frye's (1957) frameworks were used to examine the form and structure of the stories. This descriptive aspect of analysis is presented with and demonstrated by the summaries and restored narratives.

### **2.6.7.2 Exploring the hows: Analysis of performance**

The structural analysis described above has looked at the coherence of the stories. However, focussing on the broad storyline can offer too general a view and does not explore the way in which the narrative structures are dynamic (Phoenix *et al.*, 2010). Ageing research has paid little attention to the performance dimensions of narratives. It is hoped that this may reveal some strategies that stroke survivors build and draw upon as they make sense of their experiences (Phoenix *et al.*, 2010).

This approach is also sensitive to the diversity of stories collected and the contradictions and tensions within them and allows my role as researcher to be transparent. While there is opportunity to pay close attention to such factors, a potential limitation of this approach is that chunks of individual narratives can be separated from the context in which they were told. I hope that introducing the participants through their restored narratives prior to presenting this part of analysis will enable the reader to follow this section with sufficient awareness of the context.

#### ***Focus on narrative devices:***

The performative part of analysis teased out how the participants anchored their stories in specific points in life, clustered around events, with temporal and historic continuity, in generating their coherent narrative – what they drew on within their narratives to make sense of their experiences. These anchor points are the devices enabling turning points in narratives, used by the narrator to create sense or meaning

in their story over time. These discursive anchors can take many forms (Phoenix *et al.*, 2010).

Rather than asking “*What do these stories, told by older stroke survivors, tell us about stroke?*” the question is “*How is sense achieved and constructed in the telling within and about stroke?*”

Through close reading of the transcripts and the previous stages of analysis, a coding frame was developed which illustrated the narrative devices within the stories which helped the stroke survivors make sense of their experiences. This process was bi-directional in that participants used previous and current life events and situations to make sense of stroke, while also using their experience of stroke to make sense of their ongoing life story and ageing.

While some of these anchors undoubtedly come from idiosyncratic personal experiences in the past and present, others have clear links with society. Gee (2005) talks about discourse models being used in making sense of experiences and in building meaning. Gee distinguished between discourse as verbal interactions and Discourse, which he defines as:

*“...a socially accepted association among ways of using language, other symbolic expressions, and artefacts, of thinking, feeling, believing, valuing and acting that can be used to identify oneself as a member of a socially meaningful group or ‘social network’”*

(Gee, 1996, p. 131)

As such, Discourses weave through society, and are constantly enacted by individuals, perpetuating the norms and values of social groups. Membership of particular Discourses provides a language with which to narrate experiences (Gee, 2005). In this sense, participants (as we all do) draw on everyday societal, or ‘bigger’ discourses in their narratives to make sense of a local situation (Riessman, 1990). My reporting and discussion of these societal discourses that intertwined the participants’ narratives are woven throughout the remainder of my analysis and discussion, reflecting how these were woven through the participants’ stories.

## **2.7 Ensuring Quality in Qualitative Research**

It is important to consider the quality of qualitative research. However, there are no clear concepts like validity and reliability that can be ascertained in quantitative methodologies. Rather, it entails examining how well the research has been conducted and whether the findings can be regarded as trustworthy and useful (Yardley, 2008). This is particularly complex due to the very strength of qualitative research – the flexibility with which the researcher can explore the area of interest (Yardley, 2008).

Various authors have described guidelines to facilitate researchers' and readers' thinking about quality. I draw predominantly on Yardley's (2000) core principles which can be applied to assess quality in qualitative research. These are discussed below, in the context of the current study.

### **2.7.1 Sensitivity to context**

Qualitative research must be sensitive to the theoretical context of the research. As such, existing literature on stroke and ageing is provided in the introduction, enabling both the reader and I to be aware of what is already known and the theoretical influences that may affect the process of research (Yardley, 2000).

Yardley (2000) also highlights the importance of awareness of the socio-cultural setting of the research. This is made transparent through the descriptions of my own background and participant characteristics.

Consideration of the context within which the interviews took place also addressed the participants' perspectives and various ethical issues. Lincoln and Guba (1985) describe improving credibility by developing rapport and trust. They suggest that this facilitates understanding as well as the collaborative co-construction of meaning (Lincoln & Guba, 1985). Attempts were made to put participants at ease and develop rapport prior to and during the interview. These included meeting with participants prior to the interview and offering the choice of setting for both meetings to maximise accessibility. There were many further ethical considerations in the design of this study, which are examined in depth in section 2.5.

### **2.7.2 Commitment and rigour**

Commitment and rigour are demonstrated in various ways throughout the study. Considering methodological skill and competence, I was new to both qualitative and narrative methodology, although I did have considerable knowledge and experience working with both older people and those who have had a stroke.

This research relied heavily on the interaction between me and each participant at interview. Trust and rapport were essential to facilitate this interaction and to encourage participants to share their stories (Miller & Glassner, 1997). These conditions were developed as the participant experienced my reactions to their story, gaining a sense that they would not be judged, and that they were valued, respected and safe (Mearns, 1994; Miller & Glassner, 1997). In doing so, I drew on my person-centred counselling skills, particularly active listening and reflection. I also attended to my own body language as part of this communication, ensuring that my posture, eye contact and tone of voice were signalling my interest in what they were sharing with me. This enabled me to tune into the emotional communication during the interaction, which, combined with the skills of summarising and reflecting to check out my understanding, enabled deep exploration of the experiences (Mearns, 1994). My memos remind me that this style of summarising and reflecting was challenging at times as I ensured they were used as active listening tools for exploration rather than a means of therapeutic intervention.

Being aware of my lack of experience of narrative analysis, I read widely around the methodology, and sought appropriate academic supervision and support from a qualitative research study group. I also sought advice from Dr Rosemary Stenhouse, who was at the time a lecturer within the Nursing Studies department in the School of Health in Social Sciences at the University of Edinburgh, and has extensive experience using narrative analysis.

Considering data collection and analysis, small samples are recommended in research projects bound by the time constraints (Dallos & Vetere, 2005). A sample size of five (plus or minus two) is suggested for Clinical Psychology doctoral theses

in order to retain an idiographic focus. In line with these recommendations, this study recruited six participants.

Lincoln and Guba (1985) describe triangulation as a method to ensure that data is rich and comprehensive. The term triangulation typically refers to a navigational method of determining location using three different reference points. Originally, the use of this term within a qualitative research context also referred to a method of validating one account using the accounts of others. However, it is widely accepted within qualitative research that different people may have equally valid yet different perspectives. As such, the use of the term triangulation is more often used to refer to a method of enriching understanding by taking a number of different perspectives rather than aiming to converge on a single consistent account (Yardley, 2008). A review of literature on triangulation suggested that this approach does not strengthen a fundamentally flawed study, but it can contribute to understanding the issue under investigation (Thurmond, 2001).

Triangulation can involve a combination of theoretical perspectives, methodological approaches, data sources, investigators, or data analysis methods in order to minimise the limitations of a single approach. In this study, the sample was selected so that a range of views and perspectives (data sources) were available ensuring both depth and range of perspectives. This included a mix of men and women, ranging from 67 to 83 years of age, who had experienced one or more ischaemic or haemorrhagic strokes, and who lived alone or with other family members. The study also included four participants who had mild expressive language difficulties and two who did not.

Analysis and interpretation also entailed thorough consideration of commitment and rigour and demonstrated further levels of triangulation. I immersed myself in the data and undertook analysis at various levels, using multiple theoretical perspectives. Phoenix *et al.* (2010) describe this pluralism as more than aggregating different analyses, but enabling exploration of different layers of data, examining it from different viewpoints – again a form of triangulation as described by Yardley (2008).



A qualitative thesis study group and both academic and clinical supervisors were an integral part of analysis. This provided me with a sounding board to help me think through my analysis and included the valuable views of others. In addition, there were a number of times when my analysis was scrutinised in terms of analytic technique and to ensure that my findings were grounded in the narratives collected. An example of this was the identification of time as being a recurring narrative anchor point, as identified by my clinical supervisor during one such discussion.

Following discussion with my examiners at viva, a further step was undertaken to enhance confidence in the validity of analysis. Independent coding of a selection of transcripts is often used as a quality check, The aim of this process is not to prove reliability as it is accepted within qualitative methodology that the unique perspective of each independent researcher will shape the analytic process, but to help critical thinking about the decisions made and to ensure that the analysis is systematic and transparent and that the account produced is a credible one (King & Horrocks, 2010; Smith *et al.*, 2009).

A code-confirming strategy was conducted (King & Horrocks, 2010). This involved the paper trail of coded transcripts, restoried narratives, memos and identified anchor points being critically scrutinised by another individual. My clinical supervisor agreed to read three of the transcripts with the aim of scrutinising the procedure I followed in my coding and producing the restoried narratives to ensure that it makes sense to other people. Following my clinical supervisor's independent review, we met to discuss the outcome in detail and compare analyses and reflections.

This process revealed no disagreement regarding the coding and restoried narratives that had originally been produced. However, an additional aspect was uncovered which was not found by the original analysis. While I had worked hard to remain true to the narrative approach and not attempt a thematic analysis, on reading my analysis, my clinical supervisor suggested that a number of key ideas had not been directly described, for example, a sense of the cycle of life, and the prominence of loss and uncertainty within the narratives. These were emotional themes that may have been more readily uncovered if using a different qualitative methodology. As

these seem important in relation to the emotional context of each narrative they have been included within the initial phase of analysis which takes account of the personal context in the restoried narratives and as each participant is introduced.

Computer software, such as NVivo 7 (QSR International), has been designed to help organise qualitative data. My initial intention had been to make use of such a programme, however on reading my data I felt this would impinge on my ability to immerse myself in the data and consider the narratives at so many levels. This experience was consistent with Barbour's (2008) argument that such software can be problematic for some researchers and should not automatically be used.

### **2.7.3 Coherence and transparency**

Coherence has been achieved by presenting the study almost as a narrative in itself, although for the purposes of this piece of work it was necessary to abide by the academic structure required for a doctoral thesis. This entailed the preface stating my motivation and start point so the reader is aware of the context in which the research was conducted. My reflections are offered throughout, ensuring both coherence and transparency as the reader is taken through the research process, with final reflections appearing towards the end.

In attempt to maximise transparency, detailed descriptions of the procedure and the context in which the research took place have been provided. Further, data is presented throughout the analysis with extensive use of quotations enabling the reader to critique my interpretation.

Lincoln and Guba (1985) suggest developing an audit trail as a transparent account of the research process from design to dissemination. Throughout this study raw data, memos and process notes have been preserved.

Lincoln and Guba (1985) state that 'member checking' is a crucial technique in establishing credibility of qualitative research. This entails taking findings back to those originally interviewed, to check validity of the account. This is often done in narrative research, presenting participants with their restoried narratives (Elliott, 2005). It is argued that this can be helpful to correct errors and misinterpretations,

and to allow participants to volunteer additional information. However, criticism of this approach highlights a reliance on the assumption that there is a fixed truth that can be captured by the researcher and confirmed by the participant (Cohen & Crabtree, 2006). Rather, the narratives were co-created at one point in time and rather than representing objective truth or reality, they capture a snapshot of the participant's story at one point in time. It was possible that the process of telling the story, reflections afterwards or events that had since occurred could alter the story told. Frank (1994) explains this by drawing comparison with the notion of reliability:

*“The social scientific notion of reliability – getting the same answer to the same question at different times – does not fit here. Life moves on, stories change with that movement and experience changes. Stories are true to the flux of experience, and the story affects the direction of that flux.”*

(Frank, 1995, pp22)

Further, participants' stories were of their strokes while my story is of hearing about their strokes. This will inevitably lead to differing interpretations. It was therefore decided that member checking may not be helpful for either participants or my analysis in this study and was not carried out.

#### **2.7.4 Impact and importance**

This study was borne out of clinical observation combined with a scarcity of literature to aid clinicians working in this field. As such, the study was designed with the aim of gaining both practical and theoretical insight into the impact of stroke in older people.

As Broomfield *et al.* (2010) highlight, despite the widely recognised psychological difficulties stroke survivors face, there is as yet no evidence that psychological interventions are effective. There is also little known about the role of chronic illnesses such as stroke in ageing (Williams, 2003). To understand these post stroke difficulties further, particularly within the context of ageing, this study looked at how

stroke survivors make sense of their experiences, by listening to and interpreting their own words. This aimed to provide insight into the natural processes that occur in both those who adjust well to life after stroke, as well as those who struggle.

In my discussion, I relate my findings back to previous studies on stroke, and interpret this in the context of the ageing literature. I also propose conceptualising the impact of stroke in terms of lifespan development rather than biographical disruption or continuity, and suggest how these insights may be applied clinically. Finally, I suggest further areas of research in which to further develop these findings.

## **3 ANALYSIS**

### **3.1 Chapter Summary**

Narrative analysis, as discussed in Chapter 2, has no step by step methodology. As such, an analytic plan was developed through drawing on existing literature and close reading of the narratives. Firstly, content, form and structure are described while introducing the reader to the participants. I have decided to do so by presenting summaries of the narratives. Full restoried narratives are presented in Appendix 8 for transparency. This provides the reader with a rich description of the experiences of each participant with which the reader can make their own interpretation of my next phase of analysis which identifies the narrative devices used by the participants in their stories.

### **3.2 Introducing the Participants**

As described in the analytic plan, the first phase of analysis was to examine the *whats*, which involved looking at the content, form and structure of the narratives. This process is illustrated in this section as I provide a brief summary by way of introducing the reader to the participants and the form and structure of the narratives they shared. I have provided the full restoried narratives in Appendix 8 to illustrate the process carried out, for reference and transparency. These were constructed from listening to the recorded interviews and close reading and re-reading of both the transcripts and my memos. This process enabled me to immerse myself in the data and each participant's bigger narrative, helping me to search for the meaning of their smaller narratives which I explore in the next phase of analysis.

### 3.2.1 Participant 1

Participant 1 was a 68 year old man who lived at home with his wife. He had an ischaemic stroke 14 months prior to interview and had ongoing difficulties with fatigue and expressive language. He asked for extra time to articulate himself and prompts if he was really stuck finding the right word. He was a full time carer for his wife who had a stroke 11 years ago. He also had financial difficulties and he had recently been diagnosed with Chronic Obstructive Pulmonary Disease (COPD), which he attributed to his stroke.

Participant 1 shared an ultimately **regressive tragedy** narrative. Early in the narrative, as he told the story of coping with his wife's stroke, he described a comedy narrative, whereby a regressive narrative was transformed to become progressive as some challenges were selected and overcome while others were dismissed through values and goals being redefined. This resulted in positive features being seen in their changed life. This early part of the narrative was dominated by agency and power, with emphasis on the participant's rights and autonomy, and a problem solving approach to finding practical solutions to the many challenges.

Immediately following his own stroke, there was a great sense of uncertainty. Tragedy dominated the narrative, with dark tones despondently describing a hopeless situation which had consumed all that defined him as a person. Despite his initial progressive struggle, his regressive story told of how he had become overcome with resigned acceptance.

### 3.2.2 Participant 2

Participant 2 was a 78 year old man who had an ischaemic stroke 14 months previously. Scans showed he had a previous stroke although he had been unaware of this at the time. He had expressive language difficulties, speaking in somewhat fragmented sentences and substituting “*thingamy*” for words he could not find without interrupting his flow. He had angina and cared for his wife who had rheumatoid arthritis.

He adopted a mainly stable stance in sharing a **satirical** narrative using an objective tone in describing how his life had changed, rich in humour. A **regressive** narrative told his story of societal changes throughout his life, with a nostalgic, pessimistic tone. A more **progressive** narrative was used to describe his close familial relationships and personal sense of contentedness with an optimistic tone.

Particular weight was given to values and personal qualities developed in childhood, such as humour, which had been important in coping with life in general, particularly the experiences of stroke and ageing, suggesting a strong sense of ego integrity. There was a theme of agency in terms of how he felt about his situation emotionally as well as taking steps to promote his physical wellbeing, despite being unable to change his reduced mobility and fatigue. His narrative had a sense of awareness of the life cycle, and was of his whole life, not just life immediately before stroke to present.



### 3.2.3 Participant 3

Participant 3 was a 73 year old lady. She had an ischaemic stroke 18 months previously, and was in hospital for four months due to ongoing TIAs. She had another stroke a year ago. She had been diagnosed with rheumatoid arthritis in her 30s and had a heart attack and received angioplasty with stents<sup>7</sup> five years previously. She has lived alone since her husband's death eight years ago. She received care support twice a day.

She adopted a mainly **stable** stance in sharing a **progressive comedy** narrative with a reflective and emotional tone to describe how her life had changed since her stroke. She told of an initially regressive narrative which is transformed into a progressive narrative rich in redemption sequences as she redefined values and began to realise the positive features of her changed life, demonstrating a shift from helplessness towards agency. The narrative reflected the life cycle, and the losses and gains of each new phase.

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<sup>7</sup> Angioplasty is whereby a blocked artery is inflated with a small balloon and the arterial walls are reinforced with a tube known as a stent.

### 3.2.4 Participant 4

Participant 4 was a cheerful 67 year old man. He had an ischaemic stroke 17 months prior to interview and had a heart attack 8 years ago. He lost the tip of his finger in a work accident fifteen years ago, which he described as emotionally the most difficult experience of his life. He lived at home with his wife and was very active, playing golf or bowls every day. He was very keen to get the interview started and was concise in his explanations.

He adopted a **stable** stance in sharing a **progressive comedy** narrative with an optimistic tone to describe his experience of stroke. He reflected on previous experiences of ill health through his life to describe how he had adapted to enable his life to continue, making the most of every day and living his life to the full. His story had a strong sense of agency with a tone of minimising the stroke and emphasising living.

### 3.2.5 Participant 5

Participant 5 was an 83 year old man. He had a subdural haemorrhagic stroke 18 months previously. He previously had cancer twice and had a large tumour removed from his jaw three years ago leaving him with extensive scarring. He had expressive language difficulties following his stroke and his articulation was poor as a result of his facial surgery.

He shared a **stable comedy** narrative with a matter of fact tone to tell his story of subdural stroke, which was embedded within a story of ageing. Happening in the wake of two major battles with cancer, he minimised the experiences and impact of stroke. He displayed little emotion. He had no patience in trying to recall details, flapping his hand, suggesting frustration and impatience at his memory or word finding difficulties. He had no requests for accommodations for his expressive language difficulties, but stated that he welcomed prompts if he was stuck.

His account of the acute phase of his illness was his reconstruction based on his family's descriptions as he did not recall most of his time in hospital. He described his life and attitudes since this as the same as before his stroke, although detailed a number of changes, possibly suggesting more that his sense of self had not changed rather than his day to day life being unchanged.

His sense of time was somewhat impaired, at one point saying his stroke was 3 years ago, another saying it was 6 or 7 months ago, when it was actually 18 months ago<sup>8</sup>.

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<sup>8</sup> Participant 5 opted in but only provided his name on the reply slip. I contacted the stroke ward to find out his contact details and was given the date of admission with subdural stroke.

### 3.2.6 Participant 6

Participant 6 was an 84 year old man who had his first ischaemic stroke seven years previously. He had another fourteen months prior to interview, and a third two months prior. He had low mood and expressive language difficulties. He was very close to his ex-wife and she helped him a lot, both emotionally and practically. She was present during the interview and helped him to tell his story, particularly with details about time.

Participant 6 shared a **regressive tragedy** narrative, in which he had little sense of agency. He seemed resigned to his situation and sad that things had changed so much since his stroke. There was a sense of him feeling sidelined by society and let down by neighbours he had considered friends not visiting him since his strokes.

### **3.3 Exploration of narrative devices within stories**

After the detailed exploration of content, form and structure, the performative phase of analysis examined how the stories were anchored. These anchor points often acted as turning points or the pivots on which the stories turned. They were used by the narrators to create sense or meaning in their story over time. At times these anchors could also be described as small narratives within the stories that intertwine throughout the bigger narrative. Participants also seemed to be drawing on everyday societal Discourse (Gee, 2005). The threads of these small narratives intertwine my writing as they do the participants narratives.

I identified two levels of this sense making. Firstly, making sense of stroke in relation to other life events and experiences and secondly, making sense of life using stroke as a turning point. I will begin by discussing four anchor points for making sense of stroke.

In interview participants often began a narrative, then moved on to another, only to return to it at a later point. As such it would be almost impossible to present the narrative as it developed. In this section, I provide complete small narratives, some of which developed in this to-ing and fro-ing throughout interview. At times I have also removed the minimal encouragers that I provided as the listener, to aid the flow for the reader. On other occasions I have used some of the participant's words within my own sentences, while at other times, when the questions I asked guided the participants' responses, both voices have been included.

#### **3.3.1 Making sense of stroke using everyday resources**

##### **3.3.1.1 *My health in relation to me and others***

A prominent feature of making sense of the experiences of life after stroke involved the participants' understanding of their health. Specific health experiences were used in various ways to make sense of their experiences and return to everyday life following the acute and rehabilitation phase of their illness. Comparisons were drawn with previous episodes of ill health, and by considering others' health.

### *Previous experiences of ill health*

Stroke was compared to participants' own previous experiences of ill health to gain perspective on the struggle posed by the task of adapting life following stroke. This was used as both an anchor point to gain perspective, but also as a turning point, by considering how previous difficulties had been overcome.

Participant 4 considered his stroke as a minor event in comparison to his experience of losing the tip of his finger 15 years previously. He had described how his life was following stroke in practical terms, and I asked about his emotional experiences. He stated that losing his finger was more emotionally challenging than his stroke, responding by telling the story of how he had coped with the challenge of losing his finger tip, both integrating his stroke into his lifespan perspective, and recalling his adaptation following his accident:

*“The biggest emotional thing that’s happened to me is that ((holds up right hand with missing finger tip)). Because I was, I always worked with my hands ... I was about 54, 55 when it happened, and that emotionally was the worst thing that has happened to me ... because, ah, I was able to work way ma hands, and all of a sudden I couldn’t (.) work way ma right hand so I had to adapt it and I really got annoyed at not being able to do things way ma right hand you know, like pick things up and things like that, you know, getting into corners that I used to get into before. I mean, if I was working inside a box and I was wanting into the left hand corner I couldn’t get into the left hand corner because that wasn’t (demonstrated to me using his hands) so I had to sort of (.) you know (.) adapt my left hand and do it with my left hand, eh, kind of course a lot of the jobs had small screws and nuts and things like that ... Very frustrating at times, >but I got over that<. It took two or three years to get over that, but I just sort of, said to myself, well it’s like everything else, you’ve got to adapt, to get on way it and (.) eh, try not to show your emotions so much eh as what I did. I mean I was really, you know my daughter will tell you even more that my wife*

*will tell you (cough) I used to get really frustrated eh way things that I couldn't do. You know, but (.) >°it's ok now°< heh heh heh."*

Similarly, when talking about how she found the strength to cope after her stroke, participant 3 described drawing on her experiences of learning to do things differently with the onset of rheumatoid arthritis in her 30s. This was one of the mechanisms she used to turn from the regressive struggle she initially experienced to begin to look more positively at her future:

*"O aye, I've always (.) like when I took this rheumatoid, I had to fight that eh, I mean my youngest daughter was only 8 year old, and I couldn't even lift her up eh, and I had to learn to show my affection other ways, like, when she got bigger, she'd know that I couldn't pick her up so she used to crawl up me, ken, she got, and I feel as if it maybe made her stronger too. Because she had to do such a lot for herself, and I had to fight it as well you know (1) plus she had to fight it as well, and I feel as if (2) well (1) so that's how I felt and I thought well if I fought this rheumatoid, and it's crippling, you know, got no strength or 'at, and I thought (2) >I know stroke is bad<, I mean it <is bad>, it's the brain, can't be anything worse I feel, you know, >hitting the brain<, and I thought, I can fight it just the same, you know, there's still something there in me that can still fight, you know. Ken. (2) And I don't want to let go, I want to (2) you know, the likes of when I was in the hospital, when I first got it, like I say, yeah, ken, that low, ken, and I was like, there's nobody else that can do it for you. You've got to do it for yourself."*

Based on his previous experiences of illness, and societal Discourse on illness, participant 6's regressive narrative showed how he was puzzled by his symptoms of fatigue and lack of motivation as he had no pain:

*"I mean all the time I've had the strokes I've never had any pain. No pain at all. (2) That's what I telt the nurses why I couldnae understand it."*

It seemed that previous experiences of ill health were important in making sense of the experiences of life after stroke. This could offer hope and strength looking at previous struggles, but could also define unhelpful assumptions that acted as a barrier to understanding the impact of stroke.

### *Needing help and advice*

As well as looking back at previous experiences of ill health, the narratives also suggested that stroke posed difficulties that required a different approach to those faced earlier in life. This required help from others, either in the form of care support, or from health care providers. Realising and accepting that help and advice were needed from medical and care staff was another turning point.

During the regressive phase of her story, Participant 3 described initially fighting against the help available when she was in hospital and asked for her treatment to be stopped. As she thought about her family and drew on her experiences of arthritis, this became a progressive struggle as she ultimately gave in and accepted help. She was now glad that she had. She also described as sense of personal responsibility to act on advice offered, which was consistent with her own drive earlier in life to adapt to live with rheumatoid arthritis:

*“You’ve got to do it yourself. That’s the other thing, the other thing, I mean, yeah, you could go for exercises, and you can do that, but it’s you that’s got to do it. Ken, it’s you that’s got to do it. You know, and I suppose that there’s some people that can’t fight you know.”*

Participant 6 also struggled to admit that he needed help and to accept what was offered, which seemed consistent with a gender Discourse (Gee, 2005). Although his narrative was on the most part a regressive tragedy, he had found a turning point when he felt defeated and suicidal. This involved learning about the impact of stroke, rather than seeing his depression as a failure, thereby accepting the help available. This is illustrated by the three-way conversation below:



Ex-Wife: *"I personally think that when you realised that, because it was your mind that's been affected this time in the depression, once you realised that that was only part of how the stroke had affected your brain, you've accepted the fact that you need that bit extra help. And that's why he's going to the day hospital. Because it is a psychiatric day hospital, you realise that that's where they can give you the help"*

Me: *"Right"*

Ex-Wife: *"Because before I think you would have been very much against that"*

Participant 6: *"Uhhuh"*

Ex-Wife: *"But I think you realise that they're the people who are qualified to help you"*

Me: *"Right. So is that, if that had been depression because you weren't coping with things, you would have found that difficult to accept?"*

Participant 6: *"Yes"*

Me: *"But whenever you feel that it's part of your stroke and the symptoms that you're left [with"*

Participant 6: *"[Well, now I go and tell somebody"*

Me: *"Right"*

Participant 6: *"I don't keep it to myself anymore"*

Me: *"Right ok"*

Participant 6: *"I telt the hospital 'cause it was beating me. (2) It was beating me. (3) It was beating me"*

Me: *"You needed some help?"*

Participant 6: *"Umhum I needed help"*

Me: *"Umm"*

Ex-Wife: *"It's very difficult for a man who's been independent all his life to finally admit that he needs help (.) but he's got through that, we've all got beyond that now."*

Me: *"It sounds like that was a very big hurdle to get over, to begin to ask for some help and you realised that you needed some help [with"*

Participant 6: *"[Aye I have to go and tell somebody (2) Cos I was going to do something daft."*

Me: *"Right. Were you having thoughts about ending it all?"*

Participant 6: *((nods))*

When participant 4 described the acute event of stroke, he talked very softly, and referred to being looked after in various contexts. This being looked after seemed to be a turning point in his realisation that he was unwell. He described the consultant having “*a wee word way me about things,*” and a nurse gently guiding him “*back to bed*” when he got up in the night. He also used this soft tone to describe him looking after his friend who had a stroke on the golf course, indicating his awareness of how vulnerable his friend was feeling:

*“I says ((with compassion)) ‘°Are you all right°?’ ‘Aye I’m fine, I’m fine’. ‘°I don’t think you are.°’ ‘No, it’s alright,’ he says. ‘°Come on°’. He hit the ball off the tee and I said ‘°No,°’ I says ‘°Come on, come back to the clubhouse and we’re going to get the ambulance down.°’”*

#### *Looking at the health of others*

Another mechanism used to obtain perspective was to draw comparisons with others, for example other patients in the stroke ward. Participant 3 interestingly demonstrated how she used this strategy at different times. When she had her heart attack, she compared herself to others who had a stroke, and felt her situation was much worse, seeming to consider her illness as more serious:

*“I remember when I took my heart attack, there used to be people in the ward that ‘ad had a stroke and I used to think (.) they seem alright. You know, it might mean that they couldn’t move their arm or something like that and a just think, well, mine was bad, I had a heart attack, eh. But now I’ve changed cos I’ve had a stroke and it’s bad (.) because it affects you, more so than a heart attack, you know. It affects you mind, the way you think, and what it’s done to you, you know.”*

When she had a stroke herself five years later, looking at others’ experiences seemed to act as a turning point in reframing her own limitations following stroke. She also compared her situation with that of her mother’s day:

*“You know, it must be bad, I mean, I was in ((rehabilitation hospital)) and there was a lady, she just lives up the road, and she can’t speak, and she can’t walk, you know, and I used to think, ‘what a bloomin’ shame’, you know. At least I can communicate and I can get about a wee bit and then, like I say, I get such a lot of help now, you know, likes o’ my home-helps come in and things like that, you know. Whereas, like in my mother’s day, I don’t think there was anything like that, you know? And we get such a lot, like the Dial-a-Ride<sup>9</sup> and all they things, there’s no reason for you to be stuck you know. You can get out, but am, (2) O it’s not that bad (.) No that bad, heh heh heh.”*

Participant 4 also referred to looking at others in the stroke ward and realising things could be worse. He was just beginning to feel that he was returning to normal and he looked around the ward:

*“And then, of course being in the hospital, eh, I think it helped me as well, cos I was, a couple of people came in that were a lot worse than what I was, and then the lad that was in the next bed to me, after the second day he came in and he had had his <5<sup>th</sup> stroke>. And he <Couldn’t. Lift. His. Left. Foot. Off. The. Ground.> at all. It was (dragged foot about floor) scraping it along the ground.”*

Looking at others beyond the hospital setting was also evident. Participant 4 described thinking about his father’s experience of regaining use of his leg following a stroke 30 years ago, when medicine was not so advanced. Participant 2 also used comparison with others as he described, with a sense of agency, that it was each individual’s choice how well they cope after stroke, particularly drawing on witnessing a friend *“letting it rule him.”* When asked if we had covered everything at the end he said:

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<sup>9</sup> Dial a Ride is a local bookable door-to-door bus service for those with mobility difficulties.

*Just that if somebody gets to ken what I've been speaking about it'll maybe help them to come along and well (.) that boy seems to be happy, why can I no' be happy? (.) Just something on that sorta line, ken, but if you think about it, you just get miserable and life's no worth living then is it? You just have to get on and do what ye can do, no use worrying about it."*

### *Beliefs about illness*

Despite participants' consideration their own health and that of others being shown to be an important narrative anchor and often a turning point within all of the narratives I collected, I was surprised to hear some incorrect information and the clinician in me struggled not to correct this! I initially thought that some of the participants may not have received sufficient information regarding their illness, and therefore continued to hold the belief that, for example stroke is brought on by overexertion.

Participant 2 stated that:

*"I got tae slow doon a bit just in case a erupt something else, like a volcano or something heh heh heh".*

He also stated:

*"I was working out the back taking down a tree so a think that's what brought it on tae start wae."*

While at another point he said that antibiotics for a chest infection:

*"Jiggered up ma liver and since then this has all come about".*

In contrast to this, participant 4 seemed to have an accurate knowledge of stroke before his own, which seemed to help combat his fears about regaining his own functioning:

*"The only thing I kno-, knew about stroke was the fact that it was part of the brain that was affected, and that ah (.) sometimes it, the speech and the eh, the (.) arm or the leg*

*eh won't do what the brain tells it because that's the part o' the brain that's been damaged. And basically, that's all I knew about stroke at that time before I had wan. My father had a stroke a long long time ago, but he came back fae it as well, eh, so he was fine after a wee while but in that, in 'at time, it took a lot longer to recover, because medication etcetera wasn't the same then as what it is now, you know. (2) So, he (.) he took a long time to recover from it. He was in hospital a long time, But then, he was fine, he was walking about, he lost nothing at all."*

However, my initial thought about the knowledge participants held about stroke was called into question as I explored this further. Participant 3 also seemed to settle on a very logical explanation of stroke, but this followed a difficult process of questioning why her stroke had happened. I realised that this process was akin to that captured by models of loss and grief, with blaming and anger (e.g. Kubler-Ross, 1969), desperately trying to make sense of her experiences. She battled with thoughts that her stroke was sent as a punishment, which she ultimately made sense of by looking at babies born with disabilities who had no time to do anything wrong yet. A redemption sequence illustrated her looking at the changes in her life more positively then enabled her to see her "getting stroke" as a "lesson". She ultimately resolved this struggle by intertwining these spiritual reflections with a practical explanation of genetics and time taking its toll of the body.

*"I used to think this was a punishment for something I'd done wrong ... When I was younger, I used to think if you don't live a good life, well, it's like if we do anything wrong we get punished, don't we, ken? ... When I was little, I mean, it's not very nice to say it, but people used to say, if you don't behave yourself, the devil'll come an' get you, or you'll be ill or something like that, you know? ... I do believe in God, like, and that's why I think (2) And then I think, well, he's such a good person (.) God (.) supposed to be good, why would he send me a punishment? And give me this stroke? That's a bit silly isn't it, like? ... I don't think it's a punishment, it's not a punishment, you know, it's am (2) like I say (2) it's like why are these babies born? They haven't had time to do anything wrong*

*have they? ... So it's just, just your body isn't it? And your genes and the way you're made up ... But I don't think, no it's definitely not punishment, but I think you just think all these things, you just want to blame something, like as if, well it's not my fault, ken ... So, I think, the longer we live, it's only natural the more we'll get, you know like with stroke and things like that, you know, ken? And it's your wear and tear isn't it, like a car isn't it? My engine's starting to go heh heh heh."*

She later said:

*"But am, yeah, I just feel as if (2) >I just feel as if< the stroke has been sent to learn this lesson. You know (1) and well, it learnt us a lesson me, but (1) I just feel as if, there's more to life than just (2) >running around< and doing this, and doing that."*

Reading through participant 3's transcript, I thought that rather than this initially being a lack of knowledge about stroke, an alternative explanation could be that these are cognitive distortions. These may, for example, stem from childhood beliefs, or they may serve the function of providing control in the face of an unpredictable illness. Participant 3 was able to use a comparison with an ill baby to turn her understanding of her experience into something that she could more easily live with. In participant 2's case, his belief that he had to slow down to prevent another stroke may well be easier to live with than feeling unable to do as much as before his stroke.

### **3.3.1.2      *Me in my relationships***

A second narrative device identified in the stories of my participants was using interpersonal relationships to make sense of experiences. This mechanism was also used in various ways, both as anchor points as well as turning points:

*Who's important*

Considering those people and the relationships that are important in life was an anchor point in all of the narratives. This again took various forms, sometimes acting as a progressive turn towards a different way of thinking or coping, while at other times highlighting the sadness of lost relationships in a more regressive manner.

By means of commonly used Discourse, or societal narrative turns, participant 3 described how thoughts of *“doing myself in”* when at her lowest point in hospital found a turning point when: *“then I thought, I’ve got to come to myself eh, I thought about my family, and what it would do to them.”*

There were a number of examples of relationship changes helping participants to make sense of their stroke. Participant 4 told of how he had realised how important he was to his friends, while also realising how much support they were to him. Since he benefitted from their support during his immediate recovery, he had also been spending more time with them, such as sharing a leisurely lunch after playing golf:

Participant 4: *“I’ve got a lot of good friends, but not (1) <too> close, but eh, if anything happened, they’d be there to help (2) eh, a lot of good friends.”*

Me: *“Has em, your awareness of how good friends they are changed?”*

Participant 4: *“O yes, o yes. Naw, as I said, everybody every, all ma close all ma close friends up at the golf club were all here, eh.”*

Me: *“Did you expect that from them?”*

Participant 4: *“No, I didnae expect that at all, cos first, the second night I’d been in the hospital, there was 4 of them came down to see me, then the next night there was another 4. And then when I got out, if fact, the first 4 came back before I came out of hospital, and then there was 5 or 6 of them came down when I got home, so I was really, I’m not eh, I’m not alone, I’ve got a lot of friends.”*

However, he illustrated a continuation from his life pre-stroke as he described using humour to control what others saw in terms of how he was really feeling:

Participant 4: *“All the boys I play golf with always came down to the house, they came down to the hospital, twice to see me, and eh and eh when I got out first thing I done was come home and eh they were here. Mind you I blamed them they only came down for the beer you know hahahah. But ah I think I’m more, eh, I come out way more things like that now than I ever did now”*

Me: *“Like what?”*

Participant 4: *“Like eh, they only came down for the beer, eh, I think I attempt to make a joke of things a lot more now than what I did before. Which keeps me sane. Heheheh, I think it’s a way to cope, yeah, making a joke, everybody says you’ve always got a smile on your face, you know but eh, now even more so because I live to have a laugh, and I don’t eh (cough) don’t take things too serious now. That’s it (.) that’s me heheh”*

These realisations were not always positive, as demonstrated by those with regressive narratives. Participant 6 illustrated a regressive turn as he described his hurt and disappointment that he had not been supported by those in his local area, contributing to his sense of a lack of role in society:

Me: *“You mentioned there that part of that is because some of your friends have passed away and aren’t here anymore?”*

Participant 6: *“Umhum. Well, all of our friends round about here are not, well, >people I thought< were friends, well, they couldn’t care less”*

Me: *“Right. Is that since you’ve been less able to go out and things, they’re not coming round”*

Participant 6: *“Umhum”*

Me: *“And you feel that they couldn’t care less? Umm. And that’s since your stroke?”*

Participant 6: *“Yeah. And it hurts a bit”*

Participant 1 also described relationship losses that went along with him losing his job and the social network that accompanied his role. Only through the loss of this



social network had he realised how important it was. When describing why he hoped to keep working:

*“Am, it was to get me out, it was, plus the fact that rather than sit about in here on my own, I’d be outside and I was chatting to different people. I used to go out, I used to spend time with the first one I’d been to, because you knew if you went at a certain time you’d get a cup of tea there with this one, you got in time for the boy turning up for a bakers, you were turning up just at the time the boy was bringing the new bakery stuff in so you were buying, you were actually being given a pie. This sort of thing you know. ... I think you just got to know everybody and ah it was a fine job, I thoroughly enjoyed the job.”*

#### *Accepting guidance from others*

During the course of settling into life after stroke, a shift was described whereby relationships changed in order to maintain and promote wellbeing. Participant 4 tells a story of what he describes as maturing, whereby he has learned to listen to his wife’s concerns and advice about pacing himself, whereas prior to his stroke he would have laughed off her concerns:

Participant 4: *“Eh, I tended to try to get back into the same eh, (.) it’s not a routine, it’s just a (.) the same way of doing, the same way of living as I was before, although ((wife)) keeps me right at times heheheh. She’s always saying, right you’re no doing this, you’re no doing that. But eh, since I had the stroke aye she tends to be a wee bit over, eh eh heheheh, I suppose over the top at times (2) about not doing that. ... Well, I tend to, I mean I would sorta say, Aw, don’t say nothing, you know heheh. Just let it go, heheheh. I think I’ve matured a bit more since I had ma stroke hehehe.”*

Me: *“How do you mean?”*

Participant 4: *“Hoohoho, I don’t fight back now hehehe ... I’d a just said, well I’m going to do it anyway hohoho. So she keeps her tabs on me, she keeps me from doing stupid things like that, ken. But eh, hehehe, no we’re getting on fine, getting on fine.”*

Participant 2 also described similar changes within his relationship. Yet another story of renegotiation is that of participant 6's relationship with his ex-wife. Here, however, it almost appears that his ex-wife acts as the turning force in his both accepting help, but also in beginning to challenge old patterns of coping which were not working in his new situation since his stroke:

Ex-wife: *"There is a big difference. There is a big difference in the relationship between you and me. In that I can say things to you now that I couldn't have said to him when I was married to him. I don't let him sit and get maudling. I tell him just to get out of it."*

Me: *"What do you mean by maudling?"*

Ex-wife: *"O 'Nobody's doing anything for me. I can't do this, I can't do that'. I say 'get up and do what you can do'. I do say that to you."*

Participant 6: *"Umhum"*

Me: *"Right (looked at Participant 6) Do you notice that?"*

Participant 6: *"And I don't say anything! Heh"*

Ex-wife: *"But he would of, he would of years ago."*

Me: *"Ok (2) So what do you think that's about?"*

Participant 6: (Shrugs)

Me: *"Are you able to take advice a wee bit more? Or [*

Participant 6: *"Aye"*

Ex-wife: *"He was a very independent man and didn't take kindly to being told how he should do things. But now he's realised the difficulties he's got, and we both have to work together to help him get done what has to be done."*

Me: *"Right"*

Ex-wife: (To Participant 6) *"Would you agree with that?"*

Participant 6: *"Umhum"*

Me: *"What's that been like for you to have to have that (2) eh, it sounds like that's been a necessary change in your relationship?"*

Participant 6: *"It's been a big help"*

- Me: *“Right so it’s been a big help. Has it been difficult though to make that change?”*
- Participant 6: *“Well, it wasnae difficult. I wouldn’t say so.”*
- Ex-wife: *“He realises we’re both actually working together now to get things done (.) and it’s not, he knows it’s not a question that I feel obliged to do it. I’m doing it because I want to do it. And we have a son and we have to give him the support because he couldn’t do it on his own. So we’ve both got to work together, for his sake as well.”*
- Me: *“Right, ok. Is that a change since your stroke. You know, the being a team for you has been a change, but being a team for your son is that a change as well?”*
- Ex-wife: *“Well, no we’ve been like that ever since he’s had, ever since he was diagnosed. He wasn’t diagnosed ‘til he was 23.”*
- Me: *“O right”*
- Ex-wife: *“So we really worked together for him. What, since the past 12 years?”*
- Me: *“Right”*
- Ex-wife: *“But probably we haven’t worked together closely for you before, since the fire.”*
- Participant 6: *“Aye”*
- Ex-wife: *“And it just has to be that way (.) to make things easier for everybody.”*
- Me: *“Ummm. Sounds like a very practical way of thinking about it.”*
- Participant 6: *“Aye. It’s working for us and that’s the main thing.”*

### *The helping role*

Possibly illustrating the complex symbiotic caring relationships that so often exist in older couples as well as reflective of Discourse, an anchor point was in the role of caring for a loved one. This was used early after stroke in the two participants who had dependents at home, which seemed to instil a determination in them early on.

Participant 2 described his concern about not being able to care for his wife immediately after his stroke. In his progressive narrative, regaining this role enabled him to continue a very important duty, while realising his family are around to help him with the aspects he could not manage:

*“Ken, it (diagnosis of stroke) didn’t really worry me. I mean (2) later on I thought (1) well am I gonna be able to drive and things like ‘at (1) that was more ken, cos way the wife being disabled I was needed to get her about like, things like ‘at. That was ma worst worry, you know. Uhuh big worry, well aye, we have a awfy good family and we look after one another... ma family all around anyway, so I wouldna have need tae worry.”*

Participant 3 described a regressive struggle whereby she missed feeling useful, but in a progressive turn, found new ways to carry on this role:

*“But em, I just feel, as if, the only way now that I feel I can help people is, or feel a purpose in life, like, is am (1) doing, we always want to do something for someone, eh, makes you feel good, you know, I feel as if (2) well, I’m sitting here doing nothing you know, like a, you know, it maybe sounds silly like, but I can say to ma daughter, ‘O I’ll make that phone call for you (.) if you want’. You know and I think, well, I’ve saved her a bit of time, eh heh heh. And I feel as if it’s made me feel good, you know, to do something like that, you know, to help someone, you know, useful. It gives you a little bit of (.) makes you feel you’ve done something, you know.”*

Again, this anchor does not always represent progressive turns within narratives. Initially after his stroke Participant 1 also described his main concern being how to care for his wife. However, in his regressive narrative, over time, he selected this role as his priority over other aspects of his life. He sought purely practical ways of coping with the challenges he faced in relation to this, problem solving the challenges her condition posed. He now struggles with this main role and is frustrated by her demands which he often cannot meet, although hides this from her.

He is left with little else to give his day either structure or purpose and has a sense of failure that he cannot meet his own expectations of himself.

### **3.3.1.3      *Me and the things I do***

The day to day activities of the participants' lives carried many anchor points and were the source of various turns. There were also many threads of Discourse throughout the narratives of what they felt able or unable to do. There were many examples of slowing down in order to continue doing the things that were important. Achieving this was a common turning point. For example participant 4 described how he built himself up again after his stroke:

*“I took it easy for about six weeks, I wasn't able to drive anyway so I couldn't do anything about it ... I had tae sort of, I got my wife to take me up to the golf, after about a fortnight or three weeks. O I didn't go out much, just walked round about, walked down for my paper and back up again you know. Eh, and eh, 'at was it for the first 6 weeks and I got ma car back again ((smiles)) and I got up to the golf club and had a walk round way the boys and that. It lasted about two months, eight, ten weeks, eh and then I'd picked up the golf club then, and eh because I've got an electric buggy, it's fine. There's no stress 'n' that. And eh I started playing golf again. And em, well, I tend to play golf three times a week at least, and eh, I'm just back up from the bowling club (.) just now... But I felt, I don't think my life's changed that much in as much as I still go on holidays, eh although the insurance is very expensive now, hehehe, and eh still got ma golf, still go for, go out for evenings out and eh things like, so it's never changed me that much, I don't think I have, eh.”*

After participant 3's realisation that she “*had to come to myself*,” her story told of how she chose important aspects of her life to focus on, while letting others go. These activities seemed to be anchors in her story, which she used to maintain a sense of her identity and continuation of interests. Successful completion of such activities seemed to act as a turning point in her story. This seemed to relate closely to Selective Optimisation and Compensation in that she selected important activities

to work towards and sought new ways to achieve these goals. Examples included buying and learning to use a laptop so she could look at shops online rather than in town and using Dial-a-Ride instead of driving when she did go out. She also weighed up the pros and cons of going on holiday, and decided that while she enjoyed holidays earlier in life, the hassle of airports was not worth it anymore. A further example is provided below whereby she worked hard to be able to take the rubbish out as this was important to her sense of independence:

*“Well, like with walking, I mean, just putting the rubbish out to the bin, you know, it’s going down the steps which I find quite easy but its pulling yourself up, but I think that’s no’ only the stroke, that’s my rheumatoid. I was weak before like (.) I was a bit weak, but am (.) I just feel, I’ve got to get my strength back and if I can do that myself, gives me that bit of independence... And I can go on the, well (2) Dial-a-Ride, I mean you get such a lot of good services. You get that Dial-a-Ride and I go to the day centre and it’s something to look forward to, you know... But am, the one thing I do miss is I used to work for a charity before I had the stroke but I can’t do that now (.) because well I’ve lost the power in ma hands, can’t go on the till, can’t give folk change, and then I can’t stand too long, you know.”*

Participant 5’s physiotherapy in hospital was tailored to his interests, and he continued this when he was discharged, building up his walking distance towards the golf club – his ultimate goal being to walk the whole way there again:

*“He ((a physiotherapist)) gave me various things to do like kicking a ball and putting and so on which I took immediately to cause I played football in my youth and I still play golf... And for about a week after I came back I had various people, physiotherapists, occupational therapists or something, came to see me and help me and took me out for a walk, extending a bit every time... And soon I was able to go for walks myself here and I started to go a walk to the road across there that goes to the golf course. I went part of the way and back, wee bit further, wee bit further, and so on.”*

He also told how he had applied selective optimisation and compensation earlier in life by selecting to concentrate on teaching rather than professional football, but he continued to coach football to maintain his interest and use his skills and experience in another way.

*“Well, I was teaching at ((a local)) High School and I was playing professional football. So since then, and I played for a few years but I retired three years after that, then I realised that I was a better teacher than I was football player so I concentrated on teaching Heh heh heh But I looked after football teams. Kids’ football teams. And since I played football they respected me even more than they respected their gym teacher because I knew what I was talking about. Well, I hope I did heh!”*

However, this practical way of prioritising and adapting activities in order to keep doing them did not work for everyone. As described, Participant 1 took a very practical, problem solving approach to any hardships that came his way. This seemed to serve a practical function of coping with and adapting to changing situations, as well as enabling him to avoid some of the painful emotions that went along with his wife’s health problems. However, following his own stroke, he attempted to use these strategies, but failed as he was physically unable to meet his own expectations of himself in his role as carer and housekeeper. As he did not adapt his expectations, and was unable to compromise on doing things differently, he strove to do things as before but inevitably failed and was left feeling frustrated and guilty that he could not cope better.

Following his discharge from hospital he described his 24 hours at home prior to his wife’s return:

*“And by that time a had it all sorted in ma mind a what happened and no so much from the point of view from ma >future and that< worked out but ‘ad an idea by then how I was going to be able to cope with this. And by the time we had, ((wife)) came home again I was able to concentrate on her. You know. Cos I feel that by that time I’d had enough time to recover from it all, you know.”*

Such expectations of recovery meant that he struggled to make sense of why he has:

*“Lost a lot of things, sort of get up and go if you like ... I didn’t feel able to cope am and at the same time, it was just laziness.”*

#### **3.3.1.4 Me and my ageing**

A number of the narratives illustrated the participants making sense of their stroke in terms of their ageing. This aspect was difficult to assign to whether it was about making sense of stroke in terms of ageing or ageing in relation to stroke. However, I have decided to include this here as the following excerpts illustrate reflections on life as a whole which represented turns in the understanding of the effects of stroke. Participants 2 and 5 both wondered how much of the change they had experienced was due to stroke and how much would have happened anyway due to ageing.

Participant 2’s narrative was rich in reminiscence, tying together the different threads of his life. He made links between things he learned in childhood, applied in adulthood and now used to help him with ageing and life since his stroke, such as humour.

Participant 5 said

*“I don’t think I was ((affected by stroke)), well, mentally I don’t think I was. And physically I don’t think I was either because I probably would of been (.) in the same state physically by ageing as I would when I took the stroke. That’s my opinion anyhow. I think, I think some of it might be due to the stroke, but most of it is just getting old. And I’m 83 now, so I can, I can hardly expect to be running about kicking a football or something like that heh heh heh.”*

Later when telling me about slowing down and pacing himself more he again said:

*“Yeah but I might have been doing it anyway.”*



### 3.3.2 Using stroke to make sense of my life

It seemed that many of the narratives about the experience of stroke were embedded in the ageing experience, reflecting the life cycle. Here I outline some of the ways in which stroke was used as a turning point in a lifespan narrative, taking a developmental perspective rather than an illness perspective.

#### 3.3.2.1 Stroke as entering a new phase

Participant 3 shared a profound observation about the effects of time on the body, using the analogy of an engine. Her use of words (“*they*” and “*we’re*” in particular) illustrated how she was beginning to challenge the ageing Discourse as she saw herself as she had seen older people previously in her life, hinting at her previous assumptions about their ways:

*“You know, I mean, it’s like when you’ve been, like even myself when I was young, used to hear old people who used to ramble on, and you’d think “They’ve lost it, eh”. You know, terrible thing to say. And they most probably hadn’t, it was their way of living. Just because **they** live differently, doesn’t mean **we’re** not alright you know I mean, see ma daughter takes me out in the car and I’ll go, ‘aww look at they daffodils, aren’t they beautiful at the side of the road’ and she’d (.) ‘Aye’. She’d just go aye and think (makes a face). But they’re beautiful and I thought I remember when I used to go, it was up in ((local town)), along the side of the road, you know? I used to see them before and used to think, ‘That’s nice’, and drive on, you know. But now, I like to take a real interest, you know, like I look at them differently, it’s it’s just that you see things so differently, well I do anyway, I don’t know about anybody else like, but that’s the way I feel.”*

She went on to think about this change further, again making sense of her life as a whole following her stroke.

*“I don’t know, but I mean I was ey that busy, you know. I think what it is in life like, you grow up, you get married and you have children, you don’t have time to think for yourself really. And then you live in this rat race, you*

*know? And all trying to get on and do things, (2) which is good, you know. But then when something like this happens, I don't know, you just seem to (.) change, you know. And you think to yourself, why? Why did I not notice the trees when I was young? Or why did I never notice that? (2) >Because I never looked!< (3) I never looked really (1) cos you're ay that busy, either taking the children to school, or you're either working or either busy doing, you know, you don't notice these things. It's human nature you know as well, ken. I just feel as if this is another different part of my life, you know. Another different part of my life. And it's just unfortunate. You know, may maybe having a stroke is like, I wouldn't say done me good, cos I wouldn't say it's done me good but it's made me look at life different."*

As discussed previously, Participant 3 had been quite distressed as she had thought that her stroke was a punishment. She later reframed this, and considered it a lesson:

Participant 3: *"I think I'm blooming daft or something, but I mean it's it's (.) just (.) you look at things so entirely differently you know. But whether it's the stroke that's done that, I don't know (2) or (.) well (.) it must be. It must be. Made me look diff-, made me feel different."*

Me: *"Ok (1) wha what do you think it is about the stroke that's made you feel different?"*

Participant 3: *"Cos it's changed my life, hasn't it. (2) It's actually really changed my life, and I mean it's made me look at things differently. (2) You know, so maybe in a way (.) you know, it's been like (.) a lesson I've learned. (2) You know, I think it's a lesson I've learned and I think, (.) yes I miss being able to get up and just walk away and things like that and I'd love to be able to do it, but I can't. You've got to take an interest in something else, haven't you? You know. You can't just sit and mope. And I think that's what it is and I think your brain then decides to look at things differently."*

She elaborates on this further, indicating that the lesson is to slow down and notice things:

*“But am, yeah, I just feel as if, I just feel as if the stroke has been sent to learn this lesson. You know, and well, it learnt us a lesson me, but (2) I just feel as if, there’s more to life than just, running around and doing this, and doing that. You know, there’s more to life than that, even if you’re on your own. There’s more to life than running about.”*

While this is a clear example of a redemptive sequence, this also made me think of Erikson’s work, and taking this lifespan perspective I realised that stroke could be seen as acting as a pivot in this life long development.

### **3.3.2.2 It’s time to look after myself**

Another way in which the experience of stroke (and other health difficulties) was used as a turning point in life is illustrated by participant 4 talking about his heart attack initially and then his stroke as a turning point for health behaviours:

*“Before I had it (stroke), I’d had a heart attack 8 years ago and a from then on diet changed, everything. Everything to do with eating habits etcetera changed. And I tended to take it a lot easier, although I still went to work, I still played golf, eh, and but, not as often... I’m able to do a lot of things that eh I was able to do before. But I don’t think there’s anything that I don’t do, work so hard. I can’t work so hard because I get tired easily, you know, since I had the stroke that’s what happened. You know? So, I tend to just do so much and then stop, as you’ll see from ma front garden, I’ve only got the plants put in the one side, I haven’t got them in the other side, just do it in little bits you know so no, it’s eh (.) I don’t think it’s affected ma life too much.”*

In this example, Participant 4 does not attribute changes in his life to stroke, despite them seeming to chronologically occur soon after his stroke. While he describes

taking steps as means of preventing another stroke or heart attack, he sees this as a natural measure to take at his age:

*“No, a think, it’s just a the fact that I’m getting older and that eh (.) and a a just (.) I feel as though if I take it easier I’m gonna be, it’s gonna be better for me, you know, less chances I’ll have another stroke, less chance of me having another heart attack. If I take it easy and that, then it’s fine. That’s how I feel. I don’t know. I tend to look after myself more now that I did before, yeah.”*

### **3.3.2.3 Living vicariously through others**

Relationships were also used in new ways after stroke. Living vicariously through others was identified as a turning point towards a new way of experiencing the social world. Participant 3 illustrates this as she described taking an interest in what others are doing, and acquiring a different perspective on the different phases of life and her priorities changing, while being mindful of others’ life stage.

*“Well, anybody that comes, I, I now, I take more interest in what they are doing. It’s like as if (.) I’m not living that life myself, but I’m living their life really, through them.”*

As she described waving to the school children as they walked past her window each day, she said:

*“You know, I just love to see life going by, ken makes you feel good. Feel as if you’ve done something you know. Even though you’re not walking away with them, you know.”*

She made many references to her life having slowed down, and her escaping the rat race which enabled her to appreciate her relationships, or socio-emotional selectivity. However, she was also acutely aware of the different priorities at different phases of life:

*“Well, I just (3) em (1) I suppose I am different because (.) like (.) I’ve got more time for them, you know, whereas before, I’m not saying I didn’t take the grandchildren out,*

*and that, I did used to take the wee ones to the swing park and things, but I think I've got more time now, and I maybe take more interest in what they're doing cos I've got all the time in the world to listen to them, eh. And I like that, you know? I like to know that they're getting on, and they're all doing well, you know? But am, yeah I think I have changed, I have changed that way, like. I mean I'm not saying that I was not really interested in them, I was interested in 'em, but you're that busy getting on with your life ... I think when we live such a busy life, it's not that we don't care, it's that we don't have the time to show it."*

When describing how she would like to see more of her family she demonstrates that having a busy life is part younger adulthood:

*"But I often think, am I being a bit ((screws up face)), you know? Surely, cos I mean, like I say I know what it was like when I was young, in this, you know, bustling heh heh."*

When asked what he thought about getting older, participant 4 described how he found pleasure and motivation through the stories of his children, demonstrating generativity:

Participant 4: *"I don't want to get old heheheheh. Well I've got a young daughter, she's ((under 30)), I've got a young daughter there that eh, aye she'll say to us dae this, you'll have to dae. Aye, she keeps us going, she keeps her Mum going. No, I've never really thought about it. Five grandchildren and eh, they keep me going, eh especially eh ((Grandson)), ((Grandson)), cos when he comes down he gives me a big cuddle and that and eh, what we gonna do today Grandad? Heheh."*

Me: *"Whenever you say your daughter or your grandchildren keep you going, what do you mean by that?"*

Participant 4: *"Well, they're doing a lot of young things, eh, and they want us to join them, and I go out and join in way them. Em, I think that's basically what happens, you know. It does tend to, you know, keep you fit, and after an hour or*

*so I say, I wish I hadn't done that! Heheheheh. But naw, naw, they tend to, cos I do all the young things and you know eh, and ma daughter tae, they invite us out quite a lot you know, to do things, and all her old pals, they stay in this area, and eh, they don't leave us out, you know, all ((daughter))'s pals. ... I think it keeps us going, yeah. I think eh, plus the fact that ((daughter))'s not got any family yet, so well, that keeps us going as well, we keep badgering her heheheh. She'll say, ((wife))'ll say (.) you've not got a ring on your finger yet ((daughter)). Heheheh. So, o she's terrible, no hanging back, just right in there heheheh. So but ah, yeah, got a young family as well."*

#### **3.3.2.4 Me and my death**

Stroke acted as a turning point in a number of the narratives which related to a realisation that death was not so far away. It was an assumption that I held based on the literature that I had read and clinical experience that many stroke patients felt that they had a brush with death and they are left with a realisation that life will end, and possibly sooner than expected. There were various ways in which stroke represented a turning point in how participants thought about death.

Participant 1 told how he felt he was waiting for death, whereas before his stroke he had been enjoying life and never thought about death. He reported no suicidal thoughts, rather a lack of reason to continue living and no future. He had previously defined himself by productivity and activity and used a problem solving approach to overcome or adapt to previous challenges in life. As these strategies now failed him he felt his life had stopped:

*"Whether it's the stroke (2) whether it's getting older, I'm no' sure, you do get, well, I'm not at the stage of (2) am (1) death can come tomorrow and it wouldn't bother me. But on the other hand, I don't want to die tomorrow. Which is a strange way of looking at things, it wouldn't bother me but I don't want to die tomorrow."*

Both Participant 4 and 5 described a heightened awareness of their mortality and told the story of making the most of living.

Participant 4 talked about his motivation to play golf:

*“As a means of eh, it was a means of eh getting out and it was a means of keeping myself fit at the same time, you know, eh instead of being, I’ve heard of so many people that have retired and they sit in the house and they don’t (2) they dinnae, they don’t dae anything (1) And >they don’t last long,< you know I’ve heard, there’s too many people that I knew have done that, you know they retire one year and they’re not here a couple of years later, and that’s what I says, well, I don’t want that to happen, so that’s why I kept myself fit, kept going out, I go out in the winter as well and play golf. If we don’t get on the golf course we go out on the golf range.”*

When asked about his life philosophy, participant 4 said:

*“Well, life’s for living, that’s it. That’s what I think, you’re only here once. We’re only here once, and a (.) don’t get another chance. I’ve had 2 chances hehehe, and I just like to do what I’m doing, and keep smiling, and eh just get on with what I want to do. That’s it. It’s not stopped me from doing anything that I want to do.”*

Participant 2 described taking it easy to prevent another stroke or death. Although he said he was not bothered about dying itself, he was concerned about suffering and pain. His language of “*getting away*” to describe death struck a chord with my Grandmother’s language.

A further example is participant 5’s apparent openness to death when it comes, somewhat consistent with Erikson’s 9<sup>th</sup> stage. He also reflected on his experiences of being in remission from cancer, and viewed his ageing as a whole in the context of stroke and cancer (or vice versa)

*“Eh, I felt that I’ve a lived a reasonable time and if anything happened now I can’t complain. Just take things as they come. ... I reckon that, getting past 70, everything*

*else is a bonus. So if anything does happen to me I won't say 'Why Me?' I'll say 'Why not me?' I think that's a better attitude, and you've more chances of succeeding if you do that. ... It makes me realise I'm lucky to be alive."*

### **3.3.2.5 My experience of time**

Closely linked to the findings relating stroke with thoughts about death, are those relating to time perspective. Previous research has identified a changed future time perspective with age, and in stroke survivors. In this study, there were many examples of changes in the lived experience of present time, which seemed to be fuelled by this previously identified change in future time perspective.

Participant 2 described taking one day at a time as he did not know what was round the corner:

*"Well, I keep laughing and enjoying myself better, like because well (.) ye dinnae ken what's gonna happen, dinnae ken what's around the corner sorta thing."*

This was also illustrated by him and his wife buying things as they wanted or needed them rather than waiting for birthdays. Rather than investing for the future, they were enjoying their money now.

Participant 3 described enjoying moments and taking the time to notice.

*"You know, I'm quite enjoying the seeing the wee birds coming in the morning, you know, things like that, things that you would never have bothered with before, you take it for granted. You know, things that go on in life you know, you look at life differently. I think what it is, is when you're fit, you're that busy getting on with your whole life that you don't notice other people you know like me, or with (2) You know it maybe sound daft to you but you know I never noticed what was beautiful, you know. And like I say, the wee birds hunting for food you know and you think, well, they're only little things eh (.) and if they can do that, I'm an adult, and a human being, why can't I fight to do what I want to do. You know, I think*



*you look at things differently, I think it's cos I've had such a busy life. That you don't look at life properly."*

### **3.3.2.6 Ego integrity**

A sense of life continuity was present in many of the narratives. One example was attempting to cope with life using mechanisms that had previously been successful, such as using humour (participant 2).

Another example was having threads of identity throughout life. For example, Participant 4 described himself as always having been sporty, but he adapted this as he got older. He described how he related this to his determination, and his acknowledgement that you have to work hard for things:

Participant 4: *"I've al (.) always been sporty minded. Eh, I played football until I was 40, eh I played squash until I was 35, I used to play a lot of sport, you know, 10 pin bowling, I played that for well, yeah ((smiles)), that's another story heheh, I played, I was the Scottish champion at that ... Aye, I played for Scotland twice, and eh so yeah I've always been sporty minded, always been, and eh I still enjoy it yet eh. If I was fit enough I'd still kick a ball Heheh. When this happened ((holds up finger stump)) I think I told you last time, the doctors said that, well, eh the consultant said that 'This gentleman is determined to get back to the way he was before this happened,' although he says, he he says 'It's very difficult for him but' eh, he says 'he's doing very well with it'. So I mean I did, I just sorta said eh, get up and get on way it, you know"*

Me: *"Do you think that was a fair description that the consultant used?"*

Participant 4: *"O I think he was right in saying that I was determined. It wasn't going to stop me from doing things."*

There have already been examples which illustrate successful use of continuing themes throughout life, such as the SOC principles, and examples of when this seems to fail. Participant 6 described there being *"nothing like hoping"* as he recalled

memories from his past which related to cars and motorbikes – symbols of his independence and ability to get out and about. This seemed to be an indication of not accepting these as his past, and therefore having unrealistic expectations for the future. While this helped get him through the day, seeing these as hopes rather than memories acted as a barrier to him finding more fulfilment in his present.

Participant 6: *“There’s nothing like home”*

Me: *“Nothing like home?”*

Participant 6: *“Hoping”*

Me: *“Hoping, right. What you hoping for”*

Participant 6: *“A motor bike (3) That’ll never happen. When I took the first stroke I says that’s it.”*

Me: *“Was it after the first stroke that you stopped driving?”*

Participant 6: *“A while after it, when I took the second one, that’s it.”*

Me: *“You said there there’s nothing like hoping and dreaming of things”*

Participant 6: *“heh heh”*

Me: *“Is that something that you find gets you through the day?”*

Participant 6: *“Gets me through”*

Ex-wife: *“Get a sports car as long as you leave it to me”*

Everyone: (laughs)

Me: *“Ok, was that something you’ve always done throughout your life, had dreams and hopes and things?”*

Participant 6: *“Aye. Always had a car and that, or a motor bike. The way I liked.”*

Me: *“Uhhuh”*

Participant 6: *“I was never at home (.)”*

Me: *“Right. Always out doing something”*

Participant 6: *“Aye”*

Me: *“Umm. So how do you see yourself now?”*

Participant 6: *“Useless”*

He used the words “>*SICK*<”, “>*STUCK*<” and “>*BEAT*<” very forcefully at different times to describe how he felt in his situation.

Participant 6 successfully adjusted to retirement by using what could be described as SOC principles, remaining active doing the things he always enjoyed, such as gardening and feeling useful. His interests involved keeping busy. He now describes feeling useless, and although he does things that relate to his previous interests, such as watching gardening programmes or sitting in his garden, he becomes so frustrated at times that he shouts and swears in the garden.

### **3.4 Summary of Analysis**

This chapter has walked the reader through the various narrative devices identified that the participants used in making sense of their stroke. I separated these into making sense of stroke using everyday resources, and using stroke to make sense of life. The everyday resources included health, relationships, activities and ageing. Stroke as a turning point was associated with a new phase in life, living vicariously through others, looking after themselves, death, time and ego integrity. The ways in which these narrative devices were used by the participants was varied, drawing on past and present experiences as well as societal narratives and Discourse.

## **4 DISCUSSION**

### **4.1 Chapter Summary**

This chapter begins by interpreting the analysis within the theoretical context laid out in the introduction, which inevitably makes links with clinical practice. Strengths and limitations are then highlighted to aid the reader in interpreting the theoretical, clinical and personal implications of this study.

## **4.2 Theoretical Discussion of Findings**

In Chapter 1 I introduced the existing literature on stroke and ageing separately. This shares with the reader the process that I experienced as I designed the study, and what I drew on as I attempted to methodically make sense of the stories I collected. Here I pull this together to make sense of the narrative anchors and turning points identified in Chapter 3. In doing so, I also discuss my findings within the context of the ageing and lifespan development literature and then draw comparisons between post stroke adjustment and conceptualisations of grief.

### **4.2.1 Making sense of the use of everyday resources**

Similar to the findings of Faircloth *et al.* (2004), analysis revealed the use of everyday resources as anchors in the participants' narratives to make sense of their stroke. One such anchor was health, with participants drawing on their own previous experiences of illness, needing help and advice, comparing their own health with that of others and their beliefs about illness. Faircloth *et al.* (2004) also found the anchor of health in their participants' stroke narratives. However, they found that the presence of co-morbidities overwhelmed the impact of stroke in their participants' future narratives, despite a relatively young sample. Despite five out of the six participants in the current study having at least one co-morbidity, this effect was not present in their narratives. A possible explanation for this difference was that the participants in the study by Faircloth *et al.*, (2004) were younger and seventy per cent were still working – a lifestyle not as accommodating of the effects of such long term conditions as the retired lifestyle of my participants.

The changes arising within interpersonal relationships were widely discussed in the participants' narratives. The role of these relationships has been identified as a narrative anchor point which helped the participants in their sense making. McKevitt *et al.*'s (2004) review identified numerous qualitative studies which examined the experience of becoming an informal caregiver for a family member with stroke, highlighting the impact on family relationships and the expectations about kinship ties and obligation (McKevitt *et al.*, 2004; Johnson, 1998). The impact of stroke on the stroke survivors' experience of interpersonal relationships has, however, not been

widely researched and may require further attention in order to support families living with stroke.

I also noticed that some aspects of the narratives contained false ideas about stroke, which was also similar to the findings of Faircloth *et al.* (2004). I discuss the impact of this lack of congruence between patients and professionals knowledge further later.

McAdams (1999) identified redemption sequences in the narratives of people talking about traumatic experiences. In Chapter 1, I noted that stroke as a traumatic event had not been considered in this way. In this study, participant 3's narrative was full of explicit redemption sequences, for example, turning from seeing her stroke as punishment towards seeing it as a lesson. Narrative sequences in other participants' interviews regarding the personal meaning of illness also seemed to have a similar character, such as seeing stroke as a "*wake up call*." The objectively bad experience (stroke) was transformed, or redeemed in the personal narrative into an event that was meaningful to the individual as a transformational point in their life. This may or may not be seen as true to an outsider, but it is true for the individual and useful to them personally (Laidlaw & McApline, 2008).

#### **4.2.2 Discourse as context for narrative**

Many everyday resources drawn on in the narratives analysed in this study were the Discourses carrying the norms, values and expectations of society (Gee, 2005, Riessman, 1990). I had little understanding of Discourse until a meeting with Dr Rosie Stenhouse at the final stages of my analysis. I have found it useful to draw on such Sociological literature in making sense of the social context within which these narratives have formed. I find it helpful to think of narratives as being intertwined with threads of Discourse, which are anchored to the everyday resources discussed (health, relationships, activity and so on). Importantly, service providers knowledge is also influenced by Discourse. Becker and Kaufman (1995) identified physicians' views of stroke as being informed not only by their knowledge of physiological

processes but also by biomedical ideologies and cultural meanings associated with their patients' ages and impairments (Becker & Kaufman, 1995).

Cummings and Henry's (1961) Disengagement Theory of Ageing highlighted gender roles, which are an example of Discourse, on which it seemed that participant 6 in particular drew on in making sense of his loss of independence. The belief that health is the 'normal' condition that ought to be restored after illness is yet another a Discourse that influenced participants' expectations of recovery, often having to be challenged to make sense of the ongoing effects of stroke as a LTC (Frank, 1995).

Current ageing Discourse relates strongly with active ageing, while frailty is feared (Frank, 1995). In Western society the role of the older old has reduced, and so the wisdom that is associated with this sector of society in other cultures is often overpowered by images of frailty (Baltes & Kunzmann, 2003). The influences of such societal factors are likely to be involved to some degree in the current focus on compensation theories of ageing, such as SOC (Baltes & Baltes, 1990), with little attention being paid to theories which were borne out of different societal contexts, such as disengagement (Cummings & Henry, 1961), learned helplessness (Seligman, 1975) and learned dependency (Baltes, 1996).

The surrender to the medical profession described during the acute phase of illness and the acceptance of being looked after (as described by participants 4 and 5, for example) can be thought of as adopting the sick role (Parsons, 1951). This grants access to the Discourse regarding expectations on individuals while in this role, and of those caring for them as well as permitting time out from normal duties. It also provides them with a language with which to describe their experiences, which relates closely to their medical status (Frank, 1995). As the participants moved from an acute phase of illness into rehabilitation and beyond, there was a sense of individual effort and determination being important in recovery, which was entwined in a Discourse about taking an active role in recovery. For example participant 3 described having to "*do it yourself*", while others described their own effort to regain skills and abilities which were meaningful and important to them. This was also

found in Becker and Kaufman's (1995) study in which their participants viewed this effort and determination as crucial for recovery success.

Within their discussion of their stroke experiences, participants referred to different phases of illness. This is similar to the categorisation of acute and rehabilitation phases used in the SIGN (2008, 2010) guidelines. McKeivitt *et al.* (1997) also divided the findings of their review into acute, rehab and life after stroke phases, similar to the recommendations of stroke management (Hack et al., 2003; SIGN, 2008, 2010). In the current study, the shift that was apparent in moving from an acute phase to rehabilitation and beyond offers support for a major criticism of Parson's (1951) sick role as a concept - that chronic illnesses do not fit the criteria of a *temporary* role being adopted. As such, the importance of considering stroke survivors as collaborators in their ongoing care is reinforced in order to grant them access to this recovery Discourse. Further, when describing the sick role in postmodern society, Frank (1995) suggests that while surrendering our bodies to medicine, people try to hold onto their own stories. He calls this refusing narrative surrender, which is an exercise of responsibility. This is revealed in the participants' reconstructions of the narratives of the acute hospital phase of their stroke when they did not recall the events themselves.

The Discourse of the health and social care system at any given time therefore influences the narratives of those with health problems. This has implications not only at a clinical practise level, but at a public health level also. Public health campaigns can aim to alter these Discourses, for example the Stroke Association highlighting stroke as a medical emergency.

#### **4.2.3 Time Perspective**

Time perspective featured in a number of the narratives. Similar to the findings of Hjelmblink and Holmstrom (2006), there was a clear demarcation of life before and after stroke in many of the narratives. Even when changes were not attributed to stroke *per se*, there were differences described in life before and after stroke. For example, participants 4 and 5 described changes in energy and activity levels since



the time of their strokes, but thought the changes may have occurred by this time with ageing even if they had not had a stroke.

Other references to time perspective include participant 4's description of his experiences of stroke reinforcing his life philosophy of living life to the full while he can, while participant 3 described a heightened awareness of the present such as noticing things in her environment that she previously missed in her busy life. Time perspective has featured in the literature in various ways. In socio-emotional selectivity theory, Carstensen (1993) suggests that age-associated changes in time perspective stem from a heightened awareness of mortality and reduced future, leading to a focus on present-oriented/emotion related goals and redistribution of resources. This certainly appeared in narratives about investing in meaningful relationships and activities (participants 2, 3, 4, 5 and 6), or for those viewing stroke as a "wake up call" which provided the impetus to make good use of time (participants 2 and 4). Argen (1998) discusses changes in time perspective in the context of cognitive strategies being used to facilitate taking each day as it comes and losing interest in the things no longer functionally possible. Other such strategies have been identified in stroke survivors such as the focus on day-to-day routines that are repeated from week to week providing confidence in their near future and predictability to everyday life. Daily routine certainly featured heavily in the narratives in this study, with all participants describing details of a typical day, while I had to ask participants to compare this with a typical day pre-stroke.

#### **4.2.4 Disruption to the ageing trajectory**

Williams' (2003) review highlighted that the links between biographical disruption and ageing are unknown. While Pound *et al.* (1998) found that some stroke survivors, within one particular socio-graphic population, revealed biographical continuity, others have found narrative sequences which suggest a disruption within the autobiography of stroke survivors (Bury, 1982; Hinojosa *et al.*, 2008). The analysis of structure and performance described in Chapter 3 reveals that while some of my participants (participants 1 and 6 who shared ultimately regressive tragedy narratives) showed clear indications of what could be understood as biographical

disruption, others did not. However, those with more progressive narratives certainly did indicate that there had been some form of change in their lives. For example, participant 3 described her stroke as a turning point in her ageing and development. Similar to the findings of Becker and Kaufman (1995), there was a sense of focussing on recovery, bound within hope and agency within these progressive stories.

One of the aims of this study was to attempt to understand how this process occurs, drawing on the literature on ageing. Coleman (1999) discusses a preparedness for dealing with change as a criterion of successful ageing. There seems to be a link between the core principle in 'biographical disruption' and expectations of life and ageing.

Here I draw on Erikson's (1998) model of lifespan development, and propose that rather than stroke acting as a biographical disruption, it may be a turning point in lifespan development. The sudden onset of stroke (even in Participant 5's case of a slower onset of haemorrhagic stroke) and the realisation of what that meant acted as a turning point in their development. In 'normal' development, transitions between different stages in life are often prepared for, guided by personal, interpersonal and societal expectations. Development, as defined by Erikson's (1998) model, is often most troublesome at times of difficult, unexpected or forced transitions, for example in adolescents having to grow up faster than they had planned on the death of a parent, or at retirement. At these times, as seems to be the case with stroke, individuals are at risk of becoming consumed by the losses of the features of the previous stage of their life that were suddenly taken away from them rather than given up gradually.

In their review of the qualitative stroke literature McKevitt *et al.* (2004) identify ways in which stroke survivors respond to the changes that arise from stroke. Pound *et al.* (1999) found that stroke survivors develop their own strategies, such as tackling tasks more slowly and initiating learning and exercise (Pound *et al.*, 1999). It has also been found that survivors use strategies to maintain or re-establish a sense of continuity after the disruption of stroke (Becker, 1993; Kaufman, 1988). These

strategies could be described as selection, optimisation and compensation. Activity and selection models of ageing seem to capture helpful strategies that can be applied at such times of transition, however these principles seem to have failed some of the participants in this study. Participant 1 described successfully applying selection, optimisation and compensation to his changed life circumstances following his wife's stroke, for example, by adjusting his work circumstances to enable him to continue working, so he was able to continue to meet his financial and social needs. However, this practical problem solving approach has failed in his adjustment to his own stroke. While loss is clearly important here too, I discuss this in the next section. Thinking about ageing, it seems that participant 1's ongoing development and ageing was very much practically adaptational, rather than comprising any introspective identity change. When he suddenly lost his ability to use the practical principles that can be conceptualised by SOC, he became desolate, helpless and hopeless, all fuelled by a feeling of being useless.

Looking at stroke as an event that occurs at a point in someone's ongoing development, it seems appropriate to view stroke not so much a biographical disruption, but as a turning point in a life story. So rather than being a disruption or continuation, stroke may act as the pivot that the autobiography turns on. To illustrate this, making links with lifespan development, in some individuals, this pivot (stroke) turns the development towards Erikson's stage 8, in which activity and selection theories of ageing can helpfully explain some of the mechanisms by which individuals make sense of these changes in order to resolve the conflict between ego integrity and despair. On the other hand, stroke can represent the turning point at which individuals move beyond this active phase of ageing, towards a more frail stage, described by Joan Erikson (1998) as stage 9, or older old age. At this point more introspective strategies are required.

#### 4.2.5 An analogy with loss within lifespan perspective

*“Telling stories of illness is the attempt, instigated by the body’s disease, to give voice to an experience that medicine cannot describe. This voice is embodied in a specific person, but it is equally social, taking its speech from the postmodern times we live in. The voice of the ill person is made possible by modernist medicine, but it cannot be contained within modernist assumptions, particularly those about medical professional dominance and the narrative surrender this dominance requires.”*

(Frank, 1995, pp18)

The possible explanations I propose as I discuss beliefs about stroke in section 3.3.1.1 raise various questions about appropriate short and long term care following stroke, and the degree of information required to inform patients without removing important coping strategies. The contradictions and misconceptions revealed which could be viewed as cognitive distortions highlight the subjectivity of narrative. *“The stories we tell about our lives are not necessarily those lives as they were lived, but these stories become our experiences of those lives”* (Frank, 1995, pp22). What could be perceived as cognitive distortions identified possibly play an important role in making sense of experiences, such as what brought on stroke, in terms of their narrative.

It has been proposed that within CBT for PSD there should be an explicit awareness of the utility of the grief model as stroke is recognised as taking away an anticipated future, and intervention should explore the meaning of this loss for the individual (Broomfield *et al.*, 2010; Laidlaw, 2008). Loss was a prominent theme in all of the narratives within this study and has been extensively identified in the qualitative literature (McKevitt *et al.*, 2004; Salter *et al.*, 2008). This needs to be carefully addressed within CBT so as not to undermine important coping mechanisms. An example of when these distortions may be unhelpful is participant 1’s description of making a quick recovery physically by being up on his feet quickly after stroke, and emotionally by giving himself 24 hours to get his head around what had happened. This is analogous with denying the reality of the loss in grief (Broomfield *et al.*,

2010) These interpretations of his experiences and his expectations of quick recovery set him up to be disappointed in his subsequent lack of progress, which may be helped by an educational, or cognitive approach. However, other narratives, illustrating how the participants made sense of this themselves over time, suggest that this process was of sense making and meaning rather than logic.

Viewing stroke as a turning point within lifespan development leads me to draw comparison with how grief is supported, similar to Broomfield *et al.*'s (2010) proposals. As described previously, caution must be applied in balancing supporting a normal adjustment process and offering support to those at risk of or experiencing physical and mental health problems. In supporting grief, a clear distinction exists between grief counselling, supporting individuals through a painful yet natural process, and grief therapy, intervening with those experiencing particular difficulties (Woods, 1999, Worden, 2001). While there is evidence that psychological therapies can be effective in those with complex unresolved grief, there is no evidence that these interventions are effective in the early stages, and may actually be detrimental to the natural process of mourning (Neimeyer, 2000).

Applying this type of model to stroke, many of the participants in this study describe a painful process, not dissimilar to grief, which they needed to work through. Participant 3 explicitly states this:

Me: *“Do you think that period of, >you’re putting it as feeling sorry for yourself,< that that period when your mood was very low and you didn’t really have any hope for the future (2) Do you think that was a necessary spell to go through to get to where you are now?”*

Participant 3: *“Yeah (1) oh I think so, it’s like what they say, you go down to the depths and then you make your way up.”*

However, it seems that those who share a more regressive narrative seem to display what could be conceptualised as analogous with complex grief, as the difficulties remain some time after the initial loss. To date, such psychological presentations following stroke have mostly been understood within a psychiatric diagnostic framework as depression. Attempts have been made within the conceptualisation to offer psychotherapeutic approaches, such as CBT for post stroke depression

(Broomfield *et al.*, 2010; Lincoln *et al.*, 1997; Lincoln & Flannaghan, 2003; Rasquin *et al.*, 2009). However, after close analysis of the narratives of those who have both regressive and progressive narratives, I wonder whether pathologising such adjustment processes in this manner is the most helpful approach. For example, the cognitive distortions could be interpreted as similar to the cognitive strategy of denial or bargaining in Kubler-Ross's (1969) stages of grief. As Broomfield *et al.* (2010) explain, interventions for post stroke depression should be augmented and individually tailored based on principles of case formulation. Lifespan developmental factors should be central within this formulation.

Taking a therapeutic approach similar to that utilised in work with grief suggests that those in the early weeks and months following stroke should be supported rather than offered active intervention. This would include offering information, time and space to think and talk about their experiences. Relating this to current stepped/matched care service delivery guidelines within Clinical Psychology, this could relate to Tiers 1 and 2 of the Matrix (Scottish Government and NHS Education Board for Scotland (NES), 2008), whereby Clinical Psychologists can support the provision of health promotion and offer supervision and consultancy to other staff groups such as the CHSS nurses involved in this study.

For those who have a prolonged or complex reaction, which would include those with post stroke depression, work at Tiers 3 and 4 could offer a psychotherapeutic approach as intervention (Scottish Government and NES, 2008). As Broomfield *et al.* (2010) highlight, there is a clear rationale for why a CBT approach should be effective at this stage, however, to date no clear effects of CBT have been shown. A criticism of the CBT for PSD studies is that the intervention was offered too soon after stroke. Again, applying a similar model to that of loss, whereby support is beneficial in the early stages, more targeted intervention may be appropriate at later stages.

It would be remiss not to mention the criticism of the notion of complicated grief when using this model as an analogy. It is argued that complicated grief cannot exist in the absence of mental illnesses such as depression and post traumatic stress

disorders. Empirical studies have not yet sufficiently explored the validity of the concept of complicated grief (Bonanno, 2006).

This brings me to a complex debate regarding psychopathology. Bennett and Hacker (2003) state that:

*“It is most striking that Jerome Bruner, one of the founding fathers of the cognitive revolution that occurred in the mid twentieth century, was subsequently to “decry the cognitive revolution for abandoning ‘meaning making’ as its central concern, opting for information computation instead”.”*

(Bruner, 1990, pp137, as cited in Bennett & Hacker, 2003, pp386)

This controversial statement illustrates the complexities underpinning the way in which we as psychologists approach making sense of human experiences. The use of diagnostic categorisations, for example as laid out by the Diagnostic and Statistical Manual of Mental Disorders (DSM IV; American Psychiatric Association, 1994) is strong within the field of clinical psychology, illustrated by clinical guidelines for example. Such classifications are helpful, and arguably necessary in developing evidence based effective and efficient interventions, and supported by much empirical research. However, when considering the challenges posed by ageing, impending death or the onset of physical illness it may be helpful to step back from medical conceptualisations and draw on psychologists’ strength of holistic formulation to identify the issues that are driving the symptoms that may appear. Such an approach may help to inform appropriate interventions. As Broomfield *et al.* (2010) explain, there is a clear rationale as to why CBT should be beneficial for difficulties presenting following stroke. This study has highlighted the importance of clinicians gaining an understanding of stroke survivors’ explanatory frameworks, and the risks involved in working against them.

### 4.3 Strengths of the Study

Thinking about data as narrative opened up the possibilities of a whole variety of analytic techniques (Phoenix *et al.*, 2010). I have addressed my research question in terms of making sense of experiences rather than looking for commonalities and differences within accounts as would be the case with an IPA thematic analysis. My initial phase of analysis and the process of producing restoried narratives facilitated my immersion in the data. In particular this enabled me to develop a deep sense of the context in which the narrative devices I later identify are used.

Participants talked at length in interview and very rich data was collected. It is not an aim within narrative analysis to reach saturation and I arrived at the decision that I had sufficient data to analyse in order to address the research question. Further, openness to data and taking a variety of approaches within analysis has ensured quality throughout.

A strength of this study, particularly in relation to many other studies on stroke is my inclusion of four participants with expressive language problems. This created considerable challenges as they at times struggled to explicate what had happened. However, for reasons already outlined, I gave them a voice and have attempted to make sense of their stories alongside those without communication difficulties.

While I have looked at narratives as devices for making sense of experiences, and of sharing this sense making, the influence of language problems on the use of narratives as a means of making sense has not been explored here. Many questions remain unanswered as to how those who cannot communicate verbally, or use complex linguistic reasoning, make sense of their experiences and future research should consider what can be done to support these people.

A further strength is that I have included frail, older old participants by being flexible in my inclusion criteria by functionally assessing communication and cognitive abilities in each individual case rather than excluding such participants from the outset. This indicates that some of the ethical challenges around conducting research



with potentially vulnerable groups can be adequately addressed without detracting from scientific rigour.

#### **4.4 Limitations of the Study**

While qualitative studies can offer rich insights into the field of interest, careful consideration must be given to how the findings are interpreted within other contexts. Further research is required in order to ascertain whether the findings of this study are applicable to other individuals in other settings.

A number of potential criticisms of this study surround the sample. Five of the six participants were male. While the one female participant offered a rich narrative account, it must be stressed that the views shared in no way claim to be representative. Other published research in stroke has tended to have more men than women, or only male participants (e.g. Faircloth *et al.*, 2004). This may be due to stroke being shown to be more common in men than women. A recent review examined male/female ratios in the stroke literature. They found the mean age of FES in men was 68.9 years and in women 72.9 years. The incidence of stroke in men was 33 per cent higher and stroke prevalence was 41 per cent higher than females (Appelros *et al.*, 2009). However, stroke tends to be more severe in women, with a mortality rate of 25 per cent one month post stroke compared with 20 per cent in men. Functional outcomes and quality of life also tends to be poorer in women, after adjustment for age, pre-stroke functioning and co-morbidities (Reeves *et al.*, 2008). This is thought to be at least partially explained by women having a longer life expectancy and the incidence of stroke increasing with age. This suggests that those women who have a stroke may be less functionally able and therefore less likely to be able to participate in research.

When selecting individuals to invite to participate, the CHSS nurses may have unintentionally imposed bias on the sample. For example, those selected as suitable participants may be less disabled by their stroke than other stroke survivors. As described in Section 2.3.2 CHSS nurses were asked to invite stroke survivors with a range of characteristics, including a range of ages within the over 65 population and those who have had one stroke and those who have had more than one stroke. As a

result the range of ages included in the study was 67 to 84. Half of the participants were significantly older than the average age of FES for their gender. Two of these cases (Participants 2 and 6) had experienced previous strokes which may account for them being older than average age of FES. Additionally, it must be considered that this study took steps not to exclude those with both expressive language difficulties and those with mild cognitive impairment, who are often excluded from stroke research (Stroke Association, 2008a; Thomas & Lincoln, 2008; Townend *et al.*, 2007). This may have led to the inclusion of frailer, older participants in this study who may have otherwise been excluded.

The generic criteria of 'stroke' was utilised rather than specifying a particular classification such as ischaemic. This resulted in the recruitment of five participants who had experienced one or more ischaemic strokes and one participant who had a subdural haemorrhagic stroke. This decision was taken at the design stage following the nature of referrals to the Psychology Service for stroke survivors being generic in type of stroke. While some published studies have included both ischaemic and haemorrhagic stroke survivors (e.g. Carod-Atal *et al.*, 2008; Thomas & Lincoln, 2008), other studies have recruited participants whose stroke falls into one classification (e.g. Kauhanen *et al.*, 2000). Reasons why this may be beneficial include the difference in onset of symptoms. For example Participant 5's subdural haemorrhagic stroke had a gradual onset, with him noticing that he was unable to recall how to use a roundabout while driving in the weeks prior to his admission to hospital and subsequent diagnosis. On the other hand, the other participants who all experienced ischaemic strokes described a sudden onset to their symptoms. This difference in the nature of onset may affect the psychological impact of stroke and the subsequent adjustment process.

A further potential criticism of this study relates to lack of triangulation in terms of not member-checking and me being the sole analyst. However, as discussed in section 2.7.3, member-checking, or participant feedback, in this particular study was deemed unsuitable as the restored narratives produced in the analysis may have been distressing to read. Furthermore, it is likely that through telling their story and as time passed since the interview, the story told would be different at that point in time,

and participants may have wanted to edit it accordingly or add further details. The aim was to capture their story at one point in time. Further, my bias and the impact I have had on the process of analysis and interpretation has been made transparent throughout, and conclusions drawn are supported by quotations from the participants. Following analysis, it became obvious that most of the identified everyday resources map directly onto topics identified as interview prompts. The interview schedule itself (see Appendix 5) was read to each participant at the beginning of the interview, which was open and non specific. Further questions provided in Appendix 5 were planned as prompts if participants were unable to spontaneously tell their story. These were identified by myself through both clinical experience of what spontaneously arises when people talk about their strokes, and through examination of the literature as described in Chapter 1. In practice, no participant required the full set of prompts to be utilised although all participants were prompted at some point to offer examples, particularly at the beginning of each interview. However, the other prompts were used minimally, for example, only participant 5 required a prompt to talk about his relationships. It therefore seems unlikely that the interview schedule solely generated the identified everyday resources. It therefore seems unlikely that the interview schedule generated these everyday resources. Additionally, a second analyst was convinced by the logic of analysis and was satisfied with the evidence for the outcomes after reading the transcripts and scrutinising the coding and restoried narratives produced.

An aim of narrative analysis is to identify turning points in participants' narratives. Accordingly, if comparisons are not made spontaneously, a commonly used prompt is "How different is that from before your stroke?" (Murray, 2008). After asking such a question of each participant it seems hardly surprising that "Stroke as a turning point" arises as a key finding, and raises the question of whether this was a product of the interview design. However, this particular finding does not describe the turning points in the stroke stories, but rather stroke as a turning point in life. This was not an anticipated finding that I held prior to interview or analysis based on clinical experience or the existing literature. However, in hindsight, relating stroke to what is known about ageing, it is hardly a surprising finding.

## **4.5 Implications and Future Research**

This study was based on personal, clinical and theoretical observations. This section responds to those observations.

### **4.5.1 Theoretical implications**

From my initial clinical observations I began to examine the existing literature on stroke and ageing to try to make sense of what I was observing clinically. As described at the outset of this thesis, I struggled to tie together the many different theoretical angles which seem to converge with stroke. This study attempted to draw these together. In doing so, I propose new ways of integrating what is known about the processes of ageing and post stroke adjustment, focussing on lifespan development. How these theoretical postulations are applicable to staff at all levels as well as stroke survivors, family members and carers is wide-ranging. Further research is necessary to determine the accuracy and applicability of the suggestions.

### **4.5.2 Clinical implications**

A major driver for this research was clinical observations which were not explained by the current literature. Supporting this were two qualitative review papers which highlighted that further research was required in order to better meet the problems identified by stroke patients and their families in the longer term care of stroke survivors (McKevitt *et al.*, 2004; Salter *et al.*, 2008). Additionally, the authors highlighted that research should relate back to service delivery in order to ensure that care recipients are at the centre of service design. This study, along with recent publications such as Broomfield *et al.* (2010), has begun to shed some light on some of the aspects that I noted to be missing in informing my clinical practice and begin to address the gaps identified by McKevitt *et al.* (2004) and Salter *et al.*, (2008). The narrative anchors and turning points identified in the stories I collected may offer clinicians some guide as to areas that may be helpful to explore in therapy, while an awareness of the longer term process of adjustment experienced by a small number of stroke survivors provides a longitudinal context.

One aspect with important clinical implications is that the phases used within the narratives coincide with the existing phases of stroke described by the two SIGN guidelines (SIGN 2008; 2010). There were clear descriptions of the ending of the acute phase followed by a longer rehabilitation phase.

*Gaun Yersel'* – The Self Management Strategy for Long Term Conditions in Scotland (2008) outlined the national strategy for self management in LTCs. The Strategy calls for improving access to information as well as emotional and mental health support. This document again highlighted that a culture change is required so that those receiving and delivering services have both the confidence and capacity to work collaboratively. The findings of this study can be interpreted as support for the view of stroke as having different phases. This, along with my discussion of Discourse, highlights the role of general public health awareness about stroke in enabling realistic expectations, rapid responses to stroke as a medical emergency as well as education so survivors and health care professionals can work together collaboratively.

While the SIGN guidelines (2008) recommend the FRAMES model of behaviour change (Miller & Spilker, 2003) in the acute stage, it seems likely that this approach may be hindered by more complex underlying psychological processes, which are recognised in grief Discourse. Further research is required to better ascertain how best to support those during the acute and rehabilitation phases.

I have proposed that this study supports the use of a model analogous to that used to support and intervene in normal and complex grief. I propose that normal, healthy yet painful processes may benefit from support and information, possibly taking the form tier 1 and 2 work of health promotion, supporting other staff groups and the provision of self help material. In cases of what may be considered complex post stroke adjustment, an intervention from tiers 3 and 4 may be more appropriate. This would be designed based on individual formulations with a lifespan development perspective. Further research is required as suggested by Laidlaw and colleagues (Broomfield *et al.*, 2010; Laidlaw, 2008; Laidlaw *et al.*, 2003) to develop effective interventions for those with complex post stroke adjustment. This study begins to

inform how such interventions may be developed and piloted using narrative to guide the contextual frameworks to enhance treatments like CBT for people with stroke.

One challenge of CBT with older people that has been identified is ‘off target verbosity’ (OTV) (Clarke, 2009; Laidlaw *et al.*, 2003; Pushkar-Gold *et al.*, 1994). This refers to the excessive off topic talking that can impede CBT with older people (Laidlaw *et al.*, 2003). This may reflect mismatches in expectations between therapist and client regarding the nature and purpose of therapy (Clarke, 2009). Arbuckle and Gold (1993) found significant association with this phenomenon and specific neuropsychological impairments relating to verbal inhibition and working memory. However, it has also been suggested that the goals for verbal communication change with age as older people are more motivated to search for meaning, and convey this in their conversation, a notion supported by Carstensen’s (1993) Socio-emotional selectivity theory. This may appear to others as straying off topic (James *et al.*, 1998). While OTV may reflect difficulties with staying focussed in therapy, which may relate to avoidance of difficult thoughts, memories and emotions, this may reflect efforts to find meaning through storytelling as has been demonstrated by examining the narratives of the participants in this study. It may be helpful for clinicians undertaking clinical therapeutic roles with stroke survivors to facilitate their clients in anchoring these narrative threads, possibly using some of the anchors identified in this study in conjunction with procedural modifications. Laidlaw *et al.* (2003) recommended providing frequent summaries, eliciting feedback regularly, seeking permission to interrupt the client and active redirection to help clients with tendencies of OTV retain focus during therapy.

At the outset, reference was made to the increasing numbers of people living for longer with health problems. When discussing the endeavours to understand the older old, or the fourth age, Baltes and Smith (2003) draw attention to complex ethical dilemmas. They question the impetus to invest in extending the life span into the fourth age and suggest that such interventions may reduce the opportunities of an increasing number of people to live and die with dignity. While this is not the place for the moral and ethical discussion this issue requires, studies such as this offer helpful insights into how to support people in their 70s and 80s living with LTCs.

The more appropriate question may be regarding how we support those living with such complex health problems to ensure they live and die with dignity, rather than aiming to prolong life and reduce symptoms of distress and depression, again taking a lifespan developmental perspective.

#### **4.5.3 Personal reflections**

This thesis began with a preface introducing myself and my motivation for undertaking this research. From a clinical perspective, I feel that through the journey of this research I have gained a much richer understanding of the difficulties posed by life after stroke. At times it was difficult not to slip into clinician mode of developing a formulation to explain what I heard, or to try to pull out themes as I would if doing IPA or a thematic analysis. While these approaches would be interesting in themselves, I was interested in the narrative devices within the stories which acted as anchors and turning points in the various stories and had to hold my interpretation to later in the research process.

Despite gaining many insights, this has not taken the form of a simple answer or explanation of experiences and mechanisms used by stroke survivors. While the findings will certainly inform my work, and I hope that of others, many more questions have been raised as described above.

From a personal perspective, the journey has been exceptionally challenging. I am humbled to have had the opportunity to speak in depth with those who so generously shared their stories with me. My own personal narrative of my future has forever been changed by listening to and sharing in these stories.

## 5 CONCLUSION

Taking a story analytic approach to narrative analysis I have explored the stories told by six stroke survivors from the older adult population in the East of Scotland. The content, form and structural analysis identified a variety of narrative structures (progressive, regressive and stable) and narrative styles (comedy, satire, tragedy, and romance) used in making sense of stroke. Performative analysis revealed various narrative anchors relating to health, relationships, activity, ageing and death that were used by participants to make sense of stroke, while stroke itself was an anchor point in participants' ongoing life stories. These anchor points were used by some participants as turning points in their sense making.

These findings were interpreted in relation to theories of ageing. I suggest that a developmental approach may be helpful in understanding the experiences of stroke survivors entering frailty, rather than focussing on active ageing strategies which benefit those in the younger-old age groups. Consistent with the recommendations made by Broomfield *et al.* (2010), I propose an approach similar to that used in supporting grief as a framework to help health and social care staff and service users understand and support life after stroke.



## 6 REFERENCES

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## **7 APPENDICES**

## **Appendix 1**

### **Ethical Approval**

**WoSRES**  
**West of Scotland Research Ethics Service**

**West of Scotland REC 3**  
Ground Floor – The Tennent Institute  
Western Infirmary  
38 Church Street  
Glasgow G11 6NT  
[www.nhsggc.org.uk](http://www.nhsggc.org.uk)

Ms Susan Ross  
Specialist Psychological Practitioner  
NHS Fife Psychology Department  
Lynebank Hospital  
Halbeath Road  
Dunfermline Fife KY11 4UW

Date 30<sup>th</sup> March 2010  
Your Ref  
Our Ref  
Direct line 0141 211 2123  
Fax 0141 211 1847  
E-mail Liz.Jamieson@ggc.scot.nhs.uk

Dear Ms Ross

**Full title of study:** A narrative analysis of the accounts of Older Adults with stroke  
**REC reference number:** 10/S0709/12  
**Protocol number:** 1

Thank you for your email dated 30<sup>th</sup> March 2010. I can confirm the REC has received the documents listed below as evidence of compliance with the approval conditions detailed in our letter dated 16 March 2010. Please note these documents are for information only and have not been reviewed by the committee.

**Documents received**

The documents received were as follows:

Document	Version	Date
Covering Letter - email		30 March 2010
Participant Information Sheet: Tracked	Version 4	30 March 2010
Participant Information Sheet: Untracked	Version 4	30 March 2010

You should ensure that the sponsor has a copy of the final documentation for the study. It is the sponsor's responsibility to ensure that the documentation is made available to R&D offices at all participating sites.

<b>10/S0709/12</b>	<b>Please quote this number on all correspondence</b>
--------------------	-------------------------------------------------------

Yours sincerely

**Mrs Liz Jamieson**  
**Joint Committee Co-ordinator**

Copy to: Fiona Sloan, University of Edinburgh, Research Governance Manager  
Aileen Yell, NHS Fife R&D

## **Appendix 2**

### **Erikson's (1963) Theory of Psychosocial Development**

## Erikson's (1963) Theory of Psychosocial Development

Approximate Age	Developmental Task	Psychosocial crisis
0 – 18 months	Attachment to mother, which lays foundation for later trust in others	Trust versus mistrust
18 months – 3 years	Gaining some basic control of self and environment (e.g. toilet training, exploration)	Autonomy versus shame and doubt
3 – 6 years	Becoming purposeful and directive	Initiative versus guilt
6 years – puberty	Developing social, physical and school skills	Competence versus inferiority
Adolescence	Making transition from childhood to adulthood; developing a sense of identity	Identity versus isolation
Early Adulthood	Establishing intimate bonds of love and friendship	Intimacy versus isolation
Middle Adulthood	Fulfilling life goals that involve family, career and society; developing concerns that embrace future generations	Productivity versus stagnation
Late Adulthood	Looking back over one's life and accepting it's meaning	Integrity versus despair

## **Appendix 3**

### **Recruitment Pack**

Letter of invitation to participants and opt-in slip

Participant Information<sup>10</sup>

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<sup>10</sup> The title of the study was changed when writing the thesis. The letter of invitation, participant information and consent forms that were used (with the old title) are included here.



## **Dunfermline & West Fife CHP**

Clinical Psychology  
Older People's Service

Lynebank Hospital  
Halbeath Road  
DUNFERMLINE  
KY11 4UW  
Tel: 01383 565393 or 565402  
Fax: 01383 565409  
Website: [www.dwfchp.scot.nhs.uk/psychology](http://www.dwfchp.scot.nhs.uk/psychology)  
[www.moodcafe.co.uk](http://www.moodcafe.co.uk)

**Private and Confidential**  
Copyright to Susan Ross

Date: 1st March 2010  
Dictated:  
Your Ref:  
Our Ref: SR 10/S0709/12 V1  
Enquiries to: 01383 565393  
Mary Cunningham  
Email:

Dear Sir/Madam

## **RE: Research study – Reframing life after stroke in Older Adults**

You are invited to take part in a research study which is designed to explore your experience of having a stroke and the impact it has had on you and your life.

Your Chest Heart & Stroke Scotland (CHSS) Nurse was asked to send the envelope you have received to people who would be suitable to take part in this study. Your contact details have not been given out and if you decide not to take part you will not be contacted again.

Information about this study is enclosed in the Participant Information document. If you wish, feel free to discuss it with your family or friends.



If you would like to find out more about the study or would like to take part please complete the tear-off slip below and return in to me in the pre-paid envelope enclosed. I will then contact you to answer any questions you have and, if you wish, to arrange a suitable appointment. You can also telephone me on 01383 565393 if you prefer.

If I do not hear from you I will assume that you do not wish to take part and you will not be contacted again.

Thank you for taking the time to read this letter.

Yours faithfully

Susan Ross  
Specialist Psychological Practitioner  
Older People's Service

-----✂-----

Consent to contact by telephone

I would like to receive a telephone call to find out more information about the research study "Reframing life after stroke in Older Adults".

Name: (please print) \_\_\_\_\_

Contact Number: \_\_\_\_\_

Preferred time to call (between Mon-Fri, 9am-5pm):

\_\_\_\_\_

Signature: \_\_\_\_\_ Date: \_\_\_\_\_



# **Reframing Life After Stroke in Older Adults**

## **Participant Information**

Reframing Life After Stroke in Older Adults  
Participant Information

10/S0709/12

Version 4  
30<sup>th</sup> March 2010

### ***1. What is the purpose of the study?***

You have been invited to take part in a research study which is designed to explore your experience of having a stroke and the impact it has had on you and your life.

If you decide to participate in the study, you may be invited to take part in two interviews with the principle researcher, Susan Ross (Specialist Psychological Practitioner). If you opt-in to the study it is possible that you may not be selected to take part.

### ***2. How did you get my contact details?***

Your Chest Heart & Stroke Scotland (CHSS) Nurse was asked to send the envelope you have received to people who may be suitable to take part in this study.

Your contact details have not been given out. If you decide not to take part you will not be contacted again.

### ***3. Why have I been chosen?***

To help us learn about the impact of stroke in the longer term it is important that we find out about the experience of stroke and the effect it has on people's lives. This information will help us to provide a more useful service.

### ***4. Do I have to take part?***

It is entirely your choice to decide whether or not to take part in the study. Your participation is voluntary and you will not receive any payment for your time. Your decision to take part or not to take part will not affect the standard of care you receive in any way. You will be given this information sheet to keep and you will be asked to sign a consent form. You can withdraw from the study at any time (even after signing the consent form) by telephoning the principle researcher and do not have to give a reason. This will not affect the care you receive from the NHS now or in the future.

### ***5. What is involved in the study?***

If you decide to participate in the study please return the ‘*consent to contact*’ opt-in slip in the stamped addressed envelope provided. The primary researcher will then telephone you. If you prefer you can telephone the primary researcher yourself to opt-in using the number below.

During this phone call you will be given the opportunity to ask any questions you have. If you then wish to continue your participation an appointment will be arranged for the primary researcher to meet with you for the initial interview. You can decide if you would prefer this to take place at your own home or in a clinic setting. You may wish to have someone with you during this visit, such as a family member or a friend.

The first interview will provide an opportunity to ask the primary researcher any questions. If you still agree to take part you will then be asked to sign the consent form. You will then be asked some questions about your stroke and your current situation, such as what professionals are involved in your care and if you have any help at home.

You may then be selected to take part in a second interview at a time and place that suits you. During the second interview you will be asked to talk about your experience of having a stroke and the impact it has had on you and your life – the study is about hearing your story.

### ***6. What if I have difficulty talking?***

People who have had a stroke often experience difficulty talking. If you experience such difficulties but would like to take part it may be possible to write or type your responses. Other suggestions about how to support your communication would be welcomed.

### ***7. Why would I not be selected?***

The study requires a small number of participants who represent a range of views. For example, a range of men and women of various different ages. If too many people opt-in to the study, the researcher may select

only some to take part in the second interview. If you opt-in to the study you may not be selected to take part.

***8. What are the possible benefits of taking part?***

There is no clinical benefit to be gained by you from participating in this study. However, your participation may provide us with valuable information about the impact of stroke and help us to improve the service we offer.

***9. What are the possible disadvantages or risks of taking part?***

We are not aware of any disadvantages or risks of taking part. Some people may find talking about their experiences distressing. If you have any concerns or any of the questions cause you any distress please mention this to the primary researcher.

If at any point during your participation in the study the primary researcher is concerned that you are struggling to cope or are distressed, your permission would be sought to contact your GP and a referral may be made to the NHS Fife Psychology Department if you wish further support. This will be discussed with you if such a situation arises. You can also contact you GP yourself if you wish

You can also speak to an independent contact within the NHS Fife Psychology Department if you wish the clinical supervisor overseeing the research:

**Dr Janice Whittick**

Consultant Clinical Psychologist - Older People with Stroke

NHS Fife Psychology Department

Stratheden Hospital

Springfield

Cupar

Fife

KY15 5RR

01334 696336

***10. Will my taking part in this study be kept confidential?***

If you consent to take part in the study the information collected will be kept strictly confidential. Your responses will be kept securely in a locked filing cabinet in the NHS Fife Psychology Department at Lynebank Hospital. All information will be anonymised prior to analysis.

You can discuss your participation with members of your family or friends if you wish.

***11. What will happen to the results of the research study?***

The findings of the study will be written up by the primary researcher, Susan Ross, Specialist Psychological Practitioner, as a thesis submitted in part fulfilment of the Doctorate of Clinical Psychology at the University of Edinburgh. The findings may also be presented at a professional conference or published in a scientific journal. Again, in these cases, all of the information presented will be anonymised which means that no information about the identity of any of the participants will be included.

A brief report summarising the findings will be available should you wish to receive this.

***12. Who is organising and funding the research?***

The study is being organised by Susan Ross, a Specialist Psychological Practitioner working in conjunction with the University of Edinburgh and the NHS Fife Psychology Department. This study is being undertaken as part of an educational qualification. There is no additional funding available for this research.

***13. Who has reviewed the study?***

The University of Edinburgh Doctorate in Clinical Psychology Programme Ethics Committee and the West of Scotland Research Ethics Service have reviewed this study under the terms of the current

Governance Arrangements for Research Ethics Committees (GAfREC) in the UK.

***14. Contact for further information***

If you wish to take part in the study or to find out more information **please complete the opt-in slip provided and return it** in the stamped addressed envelope provided.

If you prefer you can contact the principle researcher, Susan Ross, by telephone:

**Susan Ross**

**Specialist Psychological Practitioner – Older People’s Service**

NHS Fife Department of Psychology

Lynebank Hospital

Halbeath Road, Dunfermline, Fife

KY11 4UW

01383 565393

Thank you for taking the time to read this Information Sheet and for considering taking part in this study.

Please keep this information sheet

## **Appendix 4**

### **Obtaining Informed Consent**

Evaluation to Sign Consent

Consent form



## Adapted Evaluation to Sign Consent Form

Adapted from Resnick, R., Gruber-Baldini, A. L., Pretzer-Aboff, I., Galick, E., Buie, V. C., Russ, K., & Zimmerman, S. (2007). Reliability and validity of the Evaluation to Sign Consent measure. *The Gerontologist*, 47, 69–77

**PARTICIPANT NAME** \_\_\_\_\_

**Rater Name** \_\_\_\_\_

**Date of Rating:** \_\_\_\_/\_\_\_\_/\_\_\_\_

**Notes (Optional):** \_\_\_\_\_

\_\_\_\_\_  
\_\_\_\_\_

**PROCEDURE:** Make a subjective judgment regarding item 1 below. Ask the participant questions 2-6. The evaluator may select the language to use in asking the questions in order to help the participant understand them.

**SCORE**

1. Is the participant alert and able to communicate with the examiner? \_\_\_\_\_  
Yes=2; No=0 \_\_\_\_\_

2. Ask the participant if there are any potential risks incurred as a result of participation in the study.  
*0 = Do not know or incorrect risk identified;*  
*2 = able to recall there are no known risks*  
\_\_\_\_\_  
\_\_\_\_\_

3. Ask the participant to name at least two (2) things that will be expected of him/her in terms of participant cooperation during the study.  
*0 = not able to list expectations; 1 = able to list one expectation;*  
*2 = able to list two expectations*  
*Expected responses: To meet with the researcher; To take part in an interview; To talk about their stroke*  
\_\_\_\_\_  
\_\_\_\_\_

4. Ask the participant to explain what he/she would do if he/she decides that they no longer wish to participate in the study.  
*0 = doesn't know; 1 = answers but not the most appropriate response;  
2 = talk to researcher/telephone researcher's office & leave a message if not available*

---

---

5. Ask the participant to explain what he/she would do if he/she is experiencing distress  
*0 = doesn't know; 1 = answers but not the most appropriate response;  
2 = talk to researcher or GP*

---

---

6. Ask the participant to explain how participants will be selected if too many people opt-in  
*0 = doesn't know; 1 = answers but not the most appropriate response;  
2 = participants will be selected so that a range of different people take part and their selection/de-selection is not due to anything they do.*

---

---

TOTAL SCORE \_\_\_\_\_

#### SIGNATURE

I hereby certify that the above patient is alert, able to communicate and able to give acceptable answers to items 2, 3, 4, and 5 above.

\_\_\_\_\_  
Evaluator

\_\_\_\_\_  
Date



## Dunfermline & West Fife CHP

Clinical Psychology  
Older People's Service

Lynebank Hospital  
Halbeath Road  
DUNFERMLINE  
KY11 4UW  
Tel: 01383 565393 or 565402  
Fax: 01383 565409  
Website: [www.dwfchp.scot.nhs.uk/psychology](http://www.dwfchp.scot.nhs.uk/psychology)  
[www.moodcafe.co.uk](http://www.moodcafe.co.uk)

### Private and Confidential

Copyright to Susan Ross

Study Number: 10/S0709/12

Date: 1<sup>st</sup> March 2010

Participant Identification Number:

Version: 1

## CONSENT FORM

### Reframing Life After Stroke in Older Adults

Name of Researcher: Susan Ross (Specialist Psychological Practitioner)

Please initial box

1. I confirm that I have read and understand the information sheet dated ..... (version ..... ) for the above study and have had the opportunity to ask questions. ☐
2. I understand that my participation is voluntary and that I am free to withdraw at any time, without giving any reason, without my medical care or legal rights being affected. ☐
3. I understand that it is a requirement that data collected in this research be made available for scrutiny by representative from the University of Edinburgh and NHS Fife, whose role is to check that research studies are properly conducted and the interests of those taking part are adequately protected. ☐
4. I confirm that I give my permission for my GP to be informed if the primary researcher is concerned about my psychological wellbeing. ☐
5. I agree to take part in the above study. ☐

\_\_\_\_\_  
Name of Participant

\_\_\_\_\_  
Date

\_\_\_\_\_  
Signature

\_\_\_\_\_  
Name of Person taking consent  
(if different from researcher)

\_\_\_\_\_  
Date

\_\_\_\_\_  
Signature

\_\_\_\_\_  
Researcher

\_\_\_\_\_  
Date

\_\_\_\_\_  
Signature

## **Appendix 5**

### **Interview Schedule**

## **Interview Schedule**

### **Introduction**

*Thank you for agreeing to meet with me again to take part in an interview about your experiences of stroke. As we discussed last time we met, I am interested in finding out about your experience of having a stroke and how it has affected you and your life. Rather than hearing an account of what happened, I am particularly interested in hearing your story of what stroke has meant for you. That will probably mean a little bit about what your life was like before stroke, and what you knew about stroke before your own. Then a bit about what happened, who was there, what you were thinking and feeling. Then, what I'm most interested in hearing about is what life is like now since your stroke, and the meaning stroke has had for you in your life. I might ask some questions throughout to check that I have understood, or to ask you to think about some particular aspects of your story a bit more. I'll probably ask you lots of times to give me a specific example of what you're telling me about. We might go over the same stuff, but just bear with me. Although I will ask some things, this is your story, not mine, so I don't want to guide you too much.*

*How about starting off with what you knew about stroke and what it meant before your own?*

**Further questions were prepared as prompts if participants were unable to spontaneously tell their story.**

*Tell me about having a stroke?*

*What's life been like since your stroke?*

*Describe for me a typical day now?*

*What about routine activities and chores?*

*What about the things that give us a sense of who we are... hobbies or interests?*

*What about relationships?*

*How do you see or think about yourself?*

*How do you think others see or think of you?*

*How do you think about yourself in terms of getting older?*

*What about what you believe, in terms of a life philosophy, or any faith you may have?*

**If not spontaneously offered, each answer was followed up with**

*Can you give me an example of that?*

*How different, if at all, is that from before your stroke?*

**Each interview concluded with**

*How do you feel about the story you have just shared with me?*

*How do you think someone else reading or hearing it might think of it?*

## **Appendix 6**

### **Transcription notation**

## Transcription Notation

Adapted from Gail Jefferson's work as cited in Elliott (2005)

(.)	Just noticeable pause
(2)	Timed pause (seconds)
↑word, ↓word	Onset of noticeable pitch rise
I: Word [word	
P: [Word	Square brackets denote the start of overlapping speech.
.hh	In-breath
hh	Out-breath
wo(h)rd	laughter bubbling within word
heh heh	Laughter
wor-	Sharp cut off
wo:rd	Preceding sound is stretched (wo)
(      )	Unclear talk
<u>word</u>	Words spoken louder
WORD	Words shouted
°word°	quietly spoken
>word<	Faster speech
<word>	Slower speech
→	Indicator of a significant line
((sniff))	Representation of something difficult to capture phonetically, observed body language and gestures, or to highlight where I have omitted a detail for anonymity.



**Appendix 7**

**Summary of Participant Characteristics**

Pt Number	Age	Sex	Stroke History	Other Medical Problems/ Adversities	Requests	ESC Score
1	68	M	Ischaemic Stroke April 09	- COPD (suspects related to stroke) - Smoker - Carer - Financial difficulties - <b>Expressive Language Difficulties</b>	Extra time if struggling to find words rather than prompts	12
2	78	M	Ischaemic Stroke April 09 Scan showed previous stroke	- Angina - <b>Expressive Language Difficulties</b>	None – substituted words like ' <i>thingamy</i> ' for those he could not find.	12
3	73	F	Ischaemic Stroke Jan 09 Ischaemic Stroke August 09	- Rheumatoid Arthritis - MI and angioplasty (stents) 5 years ago - Carers twice a day	None	12
4	67	M	Ischaemic Stroke Jan 09	- Heart Attack and angioplasty (with stents) 8 years ago. Stopped smoking. Takes beta blockers - Lost Finger in work accident 15 years ago	None	12
5	83	M	Jan 09 Haemorrhagic (Subdural )Stroke	- Skin Cancer 8yrs ago - Cancerous tumour on jaw 3 years ago, removed but disfigured - <b>Expressive Language Difficulties</b>	None but welcomed prompts if stuck.	12
6	84	M	Ischaemic Stroke 2003 Ischaemic Stroke March 09 Ischaemic Stroke March10	- Low mood - <b>Expressive Language Difficulties</b>	Requested extra time and paper to write on if he could not find the right word	12

## **Appendix 8**

### **Restoried Narratives**

## **Restoried Narratives**

I had concerns about whether to include the restoried narratives in my final write up. I was apprehensive about including such a lot of material in an appendix, resulting in a long document. I was also concerned about confidentiality as even after removing many personal details I am aware that each participant and their close family members are likely to be able to identify themselves.

However, I feel a strong sense of responsibility to honour the stories the participants have so generously shared with me. I feel compelled to provide my readers with the context in which the quotations I have referred to occurred. As I highlight in my discussion, the meaning of stroke in someone's life is highly individual, and requires an insight into that person's complete stroke narrative in order for us as academics or clinicians to make sense of it.

Considering all of the factors around whether or not to present the reader with the restoried narratives, alongside the fact that the participants gave their consent for their stories to be shared in this way for academic purposes, I have included them here.

## Participant 1<sup>11</sup>

### *Personal context*

Participant 1 drew on his life experiences and resources picked up throughout life, such as his jobs, to try to find the practical ways of coping with and understanding his new situation. He was highly motivated to maximise his wife's quality of life, but struggled to recognise and meet his own emotional needs, often dismissing his emotions, or describing a situation to explain the struggles he had. These more practical ways of coping were no longer working for him and he was left feeling hopeless with a resigned acceptance.

### *Interpersonal context*

Participant 1 reported being motivated to participate in the study as a way to “*give something back*” for all the care both he and his wife had received. He also described feeling lonely and isolated and motivated to tell his story to listening ears. I had a sense that previously he was very social and shared his jolly personality with many in his daily routine, while being private about his challenges at home. Since his stroke his main contact had been with his wife's carers who saw his challenges at home, often offering sympathy, but the fun side of personality was rarely shown. As the interviewer, I felt incredibly privileged to be allowed a peek inside this world, and was moved by many scenes and underlying themes that were shared.

His expressive language difficulties meant that he struggled to find the word he was looking for, or his words merged into each other. I counted 40 examples of this throughout the interview. It seems appropriate to use his own words to illustrate this:

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<sup>11</sup> As a result of my awareness of Participant 1's depressive symptomatology, I discussed the option of a referral to Clinical Psychology, which he declined. I made him aware of the options available for support if he wished to seek this at a later date, including his GP, Clinical Psychology and Fife Carers Centre.

*“But a can talk to you and you can realise that at times I’m looking for words, am, not all the time, but occasionally I am, I know that myself because I’m searching for words (heh heh).... But I do know that at times my sp (2) >there you go again you see< blaaaa (heh heh heh) the way I speak, it’s the way it is.”*

### **Societal context:**

Participant 1 had a strong work ethic and worked hard in various jobs throughout his life. He found purpose and meaning in life through working hard. He never expected to be old and frail and had hoped to work until his death.

### **Beginning**

Participant 1 was a busy, cheerful man who was very sociable and enjoyed working and the routine it provided. His wife had a stroke eleven years ago. She was wheelchair bound with mild cognitive impairment. Formal carers provided support, but to care for his wife he moved from a professional job to a manual role with more flexible working hours. Following the initial uncertainties about her prognosis and disappointment that his expectations of her care were not always met, he became extremely positive about adapting to the challenges her difficulties posed and arranged many accommodations so they could make the most of their situation, such as having a lift fitted at home and a mobility car adapted for her needs so they could enjoys days out together.

Participant 1 reported a sense of life posing one challenge after another. His wife’s health deteriorated, leading to decreasing mobility and increasing pain and discomfort. They had to stop her private physiotherapy when their money ran out, and he wondered if things would have been different if they had continued this. He described how two years ago his youngest daughter, then in her 30s, died following a long illness which he nursed her through at home. Participant 1 coped with these difficulties by holding his emotions inside and keeping busy, using his account of events to tell his story. He was a jolly person who benefitted from social support, for

example, from colleagues, nursing staff and carers. When asked how he coped he stated *“You just have to get on with it”*.

### *Middle*

After turning 65, participant 1 fought hard to keep his job as it provided respite from caring for his wife and provided much needed income. He felt highly valued that his employers accommodated him. Fourteen months ago, aged 66, he was at work when he felt unwell, woozy and light headed. His right arm was very heavy and had pins and needles in it. He tried to shrug this off, literally by stretching his shoulder and arm, but eventually phoned for a colleague to come and take him to A&E. He did not know what was happening and reported that it never struck him for a moment that it was a stroke. He had blurred memories of speaking to a doctor in a cubicle in A&E and looking back he realised that he was slurring his words. He recalled being put in a machine, which he now recognised as a scanner. He realised it was stroke when he was moved to the stroke ward.

He was *“awfy quick at recovering and was able to get up and walk about within a day”*. His speech improved mostly but his arm remained *“funny”*. He was terribly worried about his wife, feeling guilty that he had not thought about her the day before when he was admitted to hospital. She had been taken to emergency respite and he was upset that he could not see her.

After five days in hospital, he got home and recalled strongly objecting to having a day at home alone before his wife returned. He said that this turned out to be the best thing ever and had been the correct decision as it gave him time to get his thoughts together and realise what had happened. He thought about his future and how he was going to be able to cope practically so he could focus on his wife when she returned.

### *Ending*

Participant 1 described huge changes in himself and life since his stroke. He had ongoing difficulties with his speech and fatigue. His story was full of loss following initial uncertainty, with particular emphasis on the loss of his *“get up and go”* and *“the will to do things”*. He lost his job as he was no longer eligible for an HGV

license and went from “*being able to bring money in to not bringing money in,*” leaving them financially strained.

As well as his ongoing fatigue and difficulties with speech he was also diagnosed with COPD, which further reduced his mobility. He felt unsteady on his feet and often had to use his wife’s lift to get upstairs. He described spending most of his time sitting alone watching television. He often recorded an old black and white movie during the day to watch in the evening. He described enjoying this, despite thinking of it as “*pathetic*” and “*stupid*”. He and his wife ordered lunch from Meals on Wheels, although he admitted frequently cancelling his, eating bread instead to save money. He had almost no social contact, went to the shops for necessities and described having no interest in chatting to old friends he meets. He no longer spent time in the garden, as he had no motivation or physical energy to do it. He had stopped going for walks and doing jigsaws which he had enjoyed with his wife.

Although participant 1 did the “*essentials*” such as washing their clothes and going to the shops for the necessities, he described how his “*standards*” had changed, and offered examples of letting the garden overgrow, only showering once a week and not shaving for weeks. He pointed out a grimy fan in the living room, which he said would have embarrassed him in the past. He said that he made great plans to change these things, that he “*should be able to sort of say to myself buck yourself up and get on way it*” but hadn’t the energy or the will to actually do it. He wondered if this was laziness, his stroke or getting older. He reflected on this stating that although he coped practically, he felt wrong inside and described seeing the stroke as the start of this. He also felt frustrated at times by his wife’s demands. Although he hid this from her, he did let it show when she called out for him during interview.

He described himself as lucky that he only had minor problems compared to other stroke patients, stating that his speech was the only lasting functional impairment. However, he described a loss of purpose, saying “*It affects you more, I feel, not in yourself, but just in your general life is, stopped, it is, in a lot of ways, it’s stopped.*” He saw himself as negative rather than his situation as negative, as he coped well with negative situations in the past. He described seeing no future, drawing the



comparison with how he and his wife used to save up for holidays, but now neither of them want holidays. He had no motivation to find practical solutions in the way that he used to rise to the challenges posed by his wife's mobility difficulties. He said "*death can come tomorrow and it wouldn't bother me (5) but on the other hand I don't want to die tomorrow.*" He contrasted this with before his stroke, when he never thought about death, and looking back concluded that he probably had assumed that he would live forever. Although he described having no religious faith and not giving any thought to what his beliefs were, he said that he often thought about meeting his daughter "*on the other side*".

## Participant 2

### *Personal context:*

Participant 2 worked hard in a variety of manual jobs throughout life, but had moved around frequently seeing his job as a means to living rather than as defining him. He said he had had a great life, and told his story with an awareness of the whole life cycle. At the end of the interview he said that telling stories was important to him and that his mother had always told him and his siblings stories as children, about her own life experiences and family history.

### *Interpersonal context:*

Before recording began the participant's wife explained that she had given him a row after the last meeting, telling him to stop being so 'witty' about stroke. I asked her what her concerns were and she said "*It's a serious thing, stroke, and he has to take it seriously, for the interview*". I asked what he thought of this, and he just laughed. I asked his wife why she thought he had been so witty and if it was only in front of me she replied that he was always like that. I thanked her for her efforts, and agreed that stroke was a serious thing. I then said to the participant that if he used humour to cope, I'd be really interested to hear about it. His wife laughed then and said, "*Aye, he uses humour to cope alright*" with a smile and laughed as she left the room!

Participant 2 stated that he had been worried about the impression he had made in the first visit and had wondered if I would be interested in his story. Despite providing lots of encouragement he checked out that he was doing ok throughout the interview, for example: "*Am I any help tae you there?*" At the end he asked: "*Are ye sure I've no been blethering a load of rubbish or anything?*"

### *Societal context:*

Participant 2 stood back and described his observations of societal changes in his lifetime, conveying a sense of being sidelined as he has got older. He talked about how good life was in the 'olden years' and had a tone of nostalgia as he compared his early years with that of younger people now.

### *Beginning*

Participant 2's father died while serving in the army during the Second World War when he was seven. His mother brought up a large family and worked full time. He said he learned to make his own fun when he was young.

He worked from age 14 to 62 in lots of jobs, and smiled as he recalled many of these. He said he had a great life and had a lot of good things. After retirement he kept in contact with some work friends and played golf with them, but many were "*away now*." He described himself as never having been a worrier. He said he had very good health throughout his life and was quite fit. He previously hadn't given his health any thought and was "*never up nor down*". He only visited his GP if he had an accident in work. He had a friend who had a stroke years ago and recalled him being miserable after it and being less active, a bit lost and unhappy. He saw this as his friend deciding to let it "*rule him*" rather than "*getting up and doing things*".

### *Middle*

Participant 2 was in the garden cutting down a tree: "*that's what brought it on to start way*". He went to bed because he felt tired and when his wife came up later to check on him his mouth was "*a bit twisted*" and he was "*slobbering when we were talking*". She phoned for an ambulance and he was taken to hospital. He remembered wondering what was going on but seemed alright after a short time.

He was admitted to a stroke ward for five days but described being "*right as rain when I was in hospital*". They were told that he had a small stroke, and he asked for Aspirin. Laughing, he recalled the doctor being "*feared because you don't get Aspirin so much now*" but when she gave him some "*I became alright again*". He had a scan and it was confirmed that he had a stroke, and that he had a minor one before. He recalled having his walking and talking checked, and found it funny that there was concern that he could not spell and he had to explain that he never could.

At this time his main worry was for his wife as he was her main carer as she had severe arthritis. He was particularly worried about not being able to drive. He also worried about not being able to play golf anymore.

### *Ending*

Since coming home he had not been able to do so much. He described this as more of a nuisance than a worry. They had family nearby and their daughter took over as his wife's main carer and he was able to drive again. He described slowing down, for example napping in the chair more often, although he had always done this to some degree as he worked shifts and preferred to nap downstairs than go to bed in the day. He tired easily and had to rest, for example after doing small jobs in the garden, whereas he used to spend all day working. He also felt the cold more and did not go out in the bad weather. He had noticed that his wife, children and neighbours are more protective of him. His wife often told him to "*watch what you're doing*" or "*take it easy*." He said he'd slowed down so as not to strain himself and was more cautious in attempt to prevent another stroke or even death. He said that he was not caught up with death, but thought that so long as he's not suffering and in pain dying "*wouldnae bother*" him. When he described the death of older family members and friends he used the phrase "*getting away*". He said he had always thought of death as part of life.

He said he still had a good life but looking around life was not so good in the outside world: "*it's boring, with people not having much in life now really, with fights and arguing... They dae ken what life is really*".

He had bought a golf scooter before his stroke as poor circulation in his legs had made it difficult to walk the course, and although he'd slowed down even more, he was still able to play golf. He said that he is not great but he enjoys it. He also went to town with his wife, and managed to get her mobility scooter in and out of the car.

He used to enjoy a drink with friends, but since his stroke he thought he had better stop drinking. He sometimes went for a bar lunch with family or out to play darts or pool, but said that he felt a bit daft going to a bar to order fresh orange juice.

He had not been getting to their caravan since his stroke and although this was partly due to his fatigue and feeling the cold, he also explained that his wife hadn't been well and another family member was very ill and they hadn't wanted to go away. He said the atmosphere is not the same anymore since their friend at the site had died and as the site was now open all year round it was getting a bit too expensive.

He saw his main purpose as keeping the family together and looking after one another. He did not see his children and grandchildren as much as he saw his when he was young, but said they had a life of their own. Laughing, he said that he enjoyed himself better now because he didn't "*know what's round the corner*" and "*takes one day at a time*". Although this is more poignant since his stroke, he said that he always made the most of things, like joking with a shop assistant to make shopping more fun, or making up games to play in the car when going on long journeys. He reflected on learning this as a child, giving the example of the treat of going to the cinema and re-enacting it for months afterwards to make their own entertainment – laughingly he sang an old song to demonstrate! He said that his fun side came from his upbringing and believed that without a doubt this had helped him cope with his stroke and getting older.

He was unsure how much was due to the stroke and how much is ageing, but as well as slowing down he described, with sadness, that he'd noticed many changes in society. He described buying in drinks at New Year but nobody came to visit, and compared this with how their house used to be full with family, friends and neighbours. He also said that he didn't think things around about were as good as they used to be when he was young, only seeing extended family and old friends at birthdays and weddings.

He also described how their view of money has changed. They worked hard earlier in life and it had paid off so they now had everything they needed. They no longer bought birthday gifts for each other, but bought things as they need them. They also got a lot of pleasure in giving money to their grandchildren: "*If ye get it noo, ye won't get it aefter!*" He again contrasted life today with the past when describing the

cost of his granddaughter's upcoming wedding compared to his own. His giving money to his family had increased since his stroke.

Participant 2 seemed to have a sense of control in keeping fit and getting on with things, such as playing golf, so the effects of stroke *"doesnae really bother me now"*. He said that it could have been worse and described slowing down. He gave various explanations for what *"brought on"* the stroke, including working in the garden, and having antibiotics for phlegm on his chest which *"jiggered up his liver, the antibiotics, and since then all this has come about"*. He also said *"But I mean, it's maybe to do way ma age, and doing things I shouldnae be doing acause o ma age, ken as a telt ye before, cutting a tree down ... and things like that and I was working too hard maybe. I think that was probably what brought the stroke on. But as I say, I've been alright since I got ma Aspirin heh heh heh"*. He also went on to say that he has *"got tae slow doon a bit just in case a erupt something else, like a volcano or something heh heh heh"*. Toward the end he said that he did not worry about having another stroke, especially as he knew that he would be well looked after, and that it did not make him feel down, he enjoyed life just the same. *"You just have tae get on and do what ye can do, no use worrying about it, ma hair's already gone grey."*

### Participant 3

#### *Personal context:*

Participant 3 had identified two previous life events which led to her questioning and redefining herself and her day to day life – the onset of arthritis and her husband's death. She drew heavily on these experiences to tell her story with a lifespan perspective, clearly describing the losses and then gains of the latter phases.

#### *Interpersonal context:*

She was keen to share her experiences and the insights she acquired. She thought that her children would think she was “*off my rocker*” if they heard her reflections. She laughed that she probably would have thought that herself a few years ago. She engaged me very personally as her audience, at one point stating:

*“If you could (.) likes of you even (.) if you could step back and look at things differently, you know, but we never do, do we?”*

#### *Societal context:*

Participant 3 embraced her new role and perspective in life and valued the insights she gained as a result. She saw these as age related with awareness that others had different perspectives depending on their own stage in life.

#### *Beginning*

Participant 3 described a happy life with her husband and children. She was diagnosed with rheumatoid arthritis in her 30s, and described her life as restricted from a young age. She relied heavily on her car to get about as walking had been difficult for a long time. She had both hips and knees replaced. As they got older her husband was her main carer and did a lot of things to help her about the house and taking her out and about. He died suddenly 8 years ago. She had a complex grief reaction, but following advice from her GP and a Psychiatrist, got involved in charity work which enabled her to feel useful in helping others. She thoroughly enjoyed this work and it kept her very busy.

She had a heart attack 5 years ago but made a good recovery following angioplasty. She recalled seeing people in hospital who had had a stroke and could not move their arm, for example, thinking “*They seem alright... Mine was bad, I had a heart attack*”. She laughed looking back thinking that she had been more ill at the time, but little did she know! She returned to her busy schedule of charity work.

### *Middle*

Participant 3 had a stroke 18 months ago. In her story, she initially did not describe the event of having her stroke, and later when asked about this, stated that “*It’s funny cause I can’t remember now!*” She then recalled sitting up in bed, sliding over and not being able to use her arm. She was initially admitted to an acute hospital. She was moved to a rehabilitation hospital where she remained for 4 months as she had a number of TIAs. A few months after being home she had another stroke, which affected her walking. She said “*it’s only but natural that it takes a little bit more away from you like*”. At this time she became very depressed, thinking “*Why me?*” She described having suicidal thoughts for about a month after her second stroke and had asked her daughter and nursing staff to stop giving her treatment. “*A think when you have a stroke, it hits you, and you’re not thinking right and that’s why I thought that, there’s just no point.*” She planned to store up medication and take an overdose, but ultimately “*just couldn’t do it (2) and then I thought, I’ve got to come to myself, eh. I thought about my family, and (2) what it would do to them*”. She also had thoughts that nobody else could do it for her, and she had to fight for herself. Looking back she said she was glad that daughter and staff did not listen to her at the time. She described that “*you go down to the depths and then you make your way up.*”

### *Ending*

Participant 3 described thinking that she must have done something wrong, and the stroke was a punishment. She described her spiritual beliefs, and how they developed throughout her childhood. She recalled thinking that we get punished if we do not live a good life. She challenged these thoughts, and wondered why God would send her a punishment by giving her a stroke if God was good. She thought



about babies being born with disabilities who had not had time to do anything wrong, so such things must not be a punishment. She reframed her beliefs from childhood, and now saw her stroke as a combination of genes and life taking its toll on the body. She also noted that *“Things happen to you, they just happen don’t they? You know, like if you go out there and you get knocked down by a bus, it’s an accident. And I feel like this stroke, (2) I feel as if, (2) it’s just one of they things”*. She compared life expectancy to that of her grandparents and said that *“I think, the longer we live, it’s only natural, the more we’ll get, you know like with strokes and things like that, you know. Ken. And it’s your wear and tear isn’t it, like a car, isn’t it. My engine’s starting to go heh heh!”* At times she had thoughts *“like I think, it’s no gonna happen again is it?”*

As time has gone on her walking and talking has improved, and although neither are as good as before her stroke, she feels that *“life’s not that bad”*. Rather than asking *“Why me?”* she now thinks *“Well, why not me?”* She had found meeting others who have had a stroke helpful and saw herself as fortunate that she could speak and make use of services available such as Dial-a-Ride. Functionally, she was restricted more than before her stroke, but was now looking at things positively.

She had given up some things that she was no longer able to do, such as gardening and crocheting although she still enjoyed using the things she had made in the past. She missed not being productive and seeing an end product. She also had to stop her work in a charity shop as she could no longer work the till, stand for long periods of time or drive. She described missing jumping in car when felt like it and the feeling of usefulness she got from working for a charity.

Other things had been adapted so she was still able to do them, such as using Dial-a-Ride buses rather than driving herself to visit friends. She said *“But there’s always something else that you can have a try at”*. She had started doing some new things, such as going to a day centre and learning to play card games on her new laptop and how to use the internet. She laughed as she said she could go round the shops on her laptop. She also reads now, and said that she was able to do things that she could not do before because she was too busy.

When reflecting on how she moved from the depression that followed her second stroke she said *“If I can fight that (rheumatoid arthritis) all them years, I can fight this stroke. You know. I mean, something that, a it’s a challenge, and I just, I just the only thing is, I keep wondering how far I can get, you know. Like I want to achieve, to do something, and I don’t think I’ll be able to do it, but I’m gonna keep trying”*. She used the example of setting herself a challenge to improve her walking so she was able to take the rubbish outside to the bin. She still struggled to pull herself back up the steps, but saw building her physical strength up to achieve this as gaining a bit of independence.

She went on to reframe her stroke as a more positive event in her life. *“It’s actually really changed my life, and I mean it’s made me look at things differently. You know, so maybe in a way (.) you know, it’s been like (.) a lesson I’ve learned. And I think, (.) yes I miss being able to get up and just walk away and things like that and I’d love to be able to do it, but I can’t. You’ve got to take an interest in something else, haven’t you? You know? You can’t just sit and mope. And I think that’s what it is and I think your brain then decides to look at things differently.”*

She described taking more interest in other people and what they are doing in their lives. She has got to know new people in her local area as they walk past her window regularly and waves to them, which gives her day structure. She enjoys making the school children smile as they wave back to her. She offered examples describing how she can live vicariously through their stories, such as going to Tesco, both recalling when she did similar things or imagining herself there, saying *“I feel as if I’m there and doing it, you know?”*

A large focus was on the realisation that life was so busy before her stroke that she did not appreciate things that were right in front of her. *“I don’t know, but I mean I was ey that busy, you know. I think what it is in life like, you grow up, you get married and you have children, you don’t have time to think for yourself really. And then you live in this rat race, you know, and all trying to get on and do things (.) which is good, you know. But then when something like this happens, I don’t know, you just seem to (.) change, you know? And you think to yourself, why? Why did I*

*no notice the trees when I was young? Or why did I never notice that? Because I never looked!"* She noted that she had been so busy she did not notice what she was missing. She now had time to spend with friends when they came to visit, whereas before was too busy. She also was able to examine her friendships and notice who she wanted to make the effort to continue to see, and who made the effort to see her. While she could see the positives in her new life, and the advantages of not being in the "rat race anymore", she did "miss it a wee bit, (2) but we don't always get what you want in life."

*"I just feel as if this is another different part of my life, you know. Another different part of my life. And it's just unfortunate, you know, may maybe having a stroke is like, I wouldn't say done me good, cos (2) >I wouldn't say it's done me good but it's< made me look at life different, you know it's made me look at (2) at other people whereas before (3) and I don't seem to get so angry now either".* When describing recently resolving a conflict with a friend, she highlighted how she would have pretended not to be bothered by such a situation in the past and would have avoided it because "we're all so frightened of hurting one another, but sometimes you've got to say things, to put things right (2) >for fear of hurting< one another". She concluded that "maybe you're more forgiving now, you know, maybe your attitude changes, and you appreciate what people give you, you now"

She seemed to be somewhat bemused by the changes in her outlook on life, and stated that she thought her daughter would think she was "off my rocker" if she heard her talking like that. Laughing, she said she would probably have thought that herself five years ago. She also cast her mind back to when she was younger and she "used to hear old people who used to ramble on, and you'd think "They've lost it, eh". You know, terrible thing to say. And they most probably hadn't, it was their way of living. Just because **they** live differently, doesn't mean **we're** not alright you know." She had an acute awareness that rather than having got things wrong earlier in life, she was now at a different stage. "I'm 73 but I don't feel 73. I mean even though I've had the stroke, I feel that inside (2) I'm still that young person." There was a sense of the continuity of herself through time. She was also aware that her children were at a different, more busy stage in their lives. "So I just, enjoy it while

*you can, eh. But ah like I say, you look at things so differently, so differently, you know, it's strange like, you know, >I mean don't get me wrong< I'd love to be back there, in the rat race again like, ken, I would love to be able to get about like and drive my car, but then I think to myself, well, this is no a bad life, is it? I get well looked after, I get my food, I can do other things, that I never had a chance to really do, you know? Yeah. You just have to give something up to gain something else. Don't you?"*

She concludes by saying that she has a different life to be led now: *"Well I feel as if (.) I feel as if my life's just as good now. You know, I feel my life's just as good. There's good things about this way, is what I mean. Take things more slowly." ... "It's life, isn't it, it's lovely (with a big smile)."*

## **Participant 4**

### *Personal context:*

Participant 4 worked hard earlier in life, but since having health problems has prioritised his family, hobbies and maintaining a healthy lifestyle.

### *Interpersonal context:*

He was impatient to begin telling his story as I was reminding him about what I was asking him to tell me. He really got in a story telling mode and was highly animated and engaging in his 'performance'. Throughout his story, there was a sense of him minimising the impact of stroke in his day to day life. Although he described recent changes which chronologically seemed to have occurred since his stroke, I felt somewhat hesitant to continually ask how things compared to pre stroke, or how he made sense of the changes he was describing.

At one point, his wife, who had been a few rooms away, went into the kitchen where she could hear our conversation. His tone lowered and he was much less descriptive while she was within earshot, taking a break to open a window as he was too hot.

### *Societal context:*

Participant 4 saw a clear role for him and wife in society, feeling included in their children and grandchildren's lives. He embraced this phase in life where he had time to prioritise the things he enjoyed.

### *Beginning*

Participant 4's father had a stroke about 30 years ago. Although it was slow and he was in hospital for a long time, he made a good recovery. From this, participant 3 knew that stroke affected the brain and often led to speech problems, and may lead to a weak arm or leg that would not do what the brain told it as a bit of the brain was damaged.

Participant 4 had a heart attack 8 years ago and had angioplasty with stents. Following this he changed his diet and took things easier. He was able to continue working and still played golf and went on holidays, but not as often as he tired easily.

### *Middle*

He retired three years ago and was beginning to settle into retirement. Eighteen months ago he got up one morning at 6am and when he put his left foot on the ground he fell back into bed. He thought it was a “*lazy leg*” from the way he had been lying on it. He went downstairs and put the kettle on, picked a cup from the cupboard, all of which he now realises he did with his right arm. As he was pouring the water into the mug he tried to hold the mug with his left hand but could not get a hold of it. He called for his wife who immediately phoned for an ambulance. His wife said to him that he was not speaking properly and he knew then that he had a stroke. He said he felt horrible and was worried about getting the movement back in his foot and hand. Looking back, he said “*I really did get a big fright*”.

He was taken to hospital, and was asked lots of questions and given some medicine. He very gently and softly described the care he received, including when the consultant came and “*had a wee word way me about things*”. He also laughed as he described how he had been told to stay in bed but got up to use the toilet in the evening and a nurse gently told him off and sent him back to bed.

He said the worst was over by the first evening and after 14 or 15 hours he felt fine. His speech and walking quickly improved and he did not notice anything wrong the next day, although the consultant told him he was still dragging his left leg a bit. After three days he was assessed by physiotherapy and proudly reported that he was back to normal and could walk, grip and balance like before. He was monitored for three more days as he had been having palpitations and there was some concern about his heart. He was then discharged home.

At home, he took it easy for about 6 weeks and was not allowed to drive. He walked about the local area to get his newspaper in the mornings and his wife drove him to the golf club to see his friends. After 6 weeks he was able to drive again and started

to do a bit more. He initially went out for walks on the golf course, but after about 10 weeks he felt himself again.

*End*

Participant 4 said *“I don’t think it’s affected ma life too much”*. He said that he did not think that life had changed and that he tried not to let it bother him. He later described it as *“trying to live the way I was living before, although I can’t do as much as I used to do.”* Since having his stroke he tired easily. Despite this, he had not given up anything that he enjoyed. He took things easier now, as he thought this was better for him and he would have less chance of having another stroke or heart attack. For example, he had the same morning routine as before his stroke, getting up, walking to the local shop to get his newspaper and coming back to enjoy a coffee, while reading the paper and doing the crossword and Sudoku. He now allowed himself more time, taking about two hours for this routine, whereas before he was keen to get on to do things.

He described how he had adapted the way he did things so he could still do the things he enjoyed. He played golf at least 3 times a week, but used a buggy as he tired easily. He spent longer with his friends after their game of golf, having a leisurely lunch before going home. He saw golf as a way of keeping fit, and in winter when the weather was too bad to play the course he practiced on the driving range. In the afternoons he often spent time in the garden, although he laughed as he said that he now did a lot more sitting than gardening. He described pacing himself in the garden, having lots of breaks and allowing himself to do things over a few days whereas in the past he would have pushed himself to finish what he had started. He described life as less stressful. He did not drive so much now and was more likely to take other transport for longer journeys, flying to visit his brother, or getting the train to visit his children a few hours away. He still went on evenings out with his friends, but drank less alcohol now, having one or two glasses of wine, and maybe a Bacardi and coke on special occasions, whereas before his stroke he drank a lot more alcohol. Now that he was not working, he went on more holidays with his wife, although he pointed out with frustration that the insurance was a lot more expensive.

Participant 4 said that he thought seeing others in hospital who were a lot worse than him helped, making him realise that he had been lucky not to have had a more serious stroke. He said to himself “*I couldda been like that, but I’m not (.) so what you do now is look after yourself*”. As time went on, he said to himself, almost as a mantra, “*I’m. not. actually. gonna. >have. another. stroke<. I’ve just got that in the back of ma head now.*” He said that this gave him the motivation to stay fit and watch his diet.

Participant 4 said “*Life’s quite good at the moment (...) It’s not the outside, it’s the inside that’s hurt*”, going on to explain that as his appearance had not changed, others would not see the affect of the stroke. He reflected on the “*worst emotional thing*” that had happened to him, which was loosing the tip of a finger in a work accident about 15 years ago. He recalled being frustrated and angry as he struggled to adapt to doing things with his left hand. After about 2 or 3 years he “*got over that*”, and said that he believed that you have to adapt to get on with it and try not to let emotions get the better of you. “*You just have to get up and get on way it*”. He was determined that stroke was not going to stop him doing things.

He also reflected on having always been sporty, playing ten pin bowling competitively, and squash and football until he was about 40. He thought that the determination and discipline of sport also helped his cope.

Participant 4 noticed how his wife was now more protective of him than before. She often said that he did too much, and said “*you’re no doing this, or you’re no doing that*”. He laughed and said she kept him right, although at times went over the top. He also noticed how he had changed in his relationships: “*Well, I tend to, I mean I would sorta say, ‘Aw don’t say nothing’, you know heh heh, ‘just let it go’ heh heh heh. I think I’ve matured a bit more since I had ma stroke heh heh heh. I don’t fight back now*”. He said before his stroke he would have been stubborn and done what he wanted anyway. He said that his wife “*keeps tabs on*” him to stop him “*from doing stupid things*”.

He also described how his friends rallied round him while he was in hospital and recuperating at home. He was pleasantly surprised by how supportive they were. He



said that he joked a lot with his family and friends which kept him sane, and it also allowed him to control what others see. He said he did not take things too seriously now. Drawing on another experience in the past, when he was 11 he had an operation for a squint. He had both eyes covered for a week, and recalled a man visiting the ward and telling jokes. He never saw him, but still remembered how good it felt to laugh.

He also described his stroke helping him, when he recognised that his friend was having one on the golf course. He told this story with compassion and respect, and described how he had gone to great efforts to protect his friend's dignity and indicated how vulnerable he knew his friend might be feeling.

He said he did not want to get old, and his daughter and grandchildren kept him going. He described how he joined in with "*young things*" and it kept him fit. Similarly, most of his golfing friends were 20 years younger. He said "*I always try to keep myself young... I'll never be young but eh heh heh heh. Keep trying (.) keep trying (...) I know I'm getting old, but eh, I put that to the back o here (points to head) and just get on with it.*"

He said that his underlying beliefs were that life was for living, and "*You're only here once. We're only here once and don't get another chance. I've had 2 chances already heh heh.*" He tried to find the fun in life, giving examples of playing games with his family on a cruise last year and dressing up in Hawaiian shirts.

He concluded his story by saying "*I'm here to live, I'm here to enjoy myself, so that's what I'm trying to do and I'll not let it keep me back, put it that way... can't let it get you down.*"

## Participant 5

### *Personal context:*

Participant 5 lived at home with his wife, and they have a mutually supportive caring relationship. He was unsentimental and matter of fact about his experiences, describing events rather than emotions, although in doing so he was able to convey a strong sense of meaning. He seemed to view a flat emotional repertoire as “*succeeding*” and made reference to not allowing himself to feel afraid or that stroke has had a negative impact on his life.

### *Interpersonal context:*

Participant 5 told me an overview of his experiences of stroke at the initial meeting, which from my perspective aimed to provide information about the study and what was involved and if appropriate attain informed consent. He then reported feeling that there wasn't much more he could contribute when I went back for interview as he had told me everything already, “*unless you can illicit it be asking different questions heh heh*”. This all initially made me wonder if he had a sense of not having a story worth telling, but on closer reading I realised that he shared a deep feeling of vulnerability when he did describe emotions.

### *Societal context:*

Participant 5 was a retired teacher and this seemed to define his role in society. He was a private man who did not seem to expect any further engagement in society than his current state enabled. His views seemed to be driven from within rather than being influenced by others or society. He did, however, share societal narratives of illness, describing asking “*Why not me?*” rather than “*Why me?*” and found comfort in a narrative commonly found in cancer survivors saying in that he had cancer and a stroke rather than having them.

### *Beginning*

Participant 5 was a professional footballer in his early twenties, when he was also a high school teacher. He had experienced various health problems in recent years.

He had skin cancer 8 years ago which was successfully treated. He developed a tumour on his jaw 3 years ago, which was removed surgically, leaving one side of his neck and face disfigured. He had known a few people who had a stroke and lost strength in their arm or leg or one side or their face. A friend who had a stroke recently, used a wheelchair or walker to get about.

### *Middle*

Eighteen months ago he had been having headaches at the back of his head which at the time he thought was sinus trouble. He now laughed at his self prescribed nasal sprays since he had learned that his sinuses were at the front of his head! About eighteen months ago he noticed that he was a bit confused about what to do at a roundabout when he was driving. He decided to stop driving in case he caused an accident for himself or anyone else. He did not feel great and a few months later he was standing in his kitchen and noticed that he was not keeping his balance very well and was swaying back and forwards. His wife told him to sit down and they got their GP out, who sent him to A&E. They found blood ‘floating’ around the back of his head, but he could not recall what it was called, “*What was the name of it? You know what it was, I think you mentioned, sub something?*”. He’d had a subdural stroke and had been told that he had been transferred to a larger hospital, although he did not remember this. They operated and successfully put in a couple of drains – he showed me the indented scars on his skull. He was doing well, but after three days was transferred back to his local hospital. He said “*maybe they were short of a bed for somebody else or something!*” He vaguely recalled being in the ambulance as he was transferred but did not recall being in the local hospital. That evening, he apparently attempted to get out of bed to go to the toilet and fell and bumped his head, giving himself a black eye – he later described this as his stroke. He was in a coma for a few days. He described feeling let down because “*I felt at that time somebody should’ve been there, to make sure I didn’t do anything daft, (.) because I wasn’t capable of looking after myself in that situation.*”

His family were all called to the hospital and kept vigil for 4 days thinking that he would not waken up. However, he did regain consciousness, while his son was at his

bedside and everyone was amazed that he'd "*come back again*". He felt well cared for after that, although he laughed saying that he suspected it may have had something to do with his wife kicking up a bit of a row about his fall. He had taught one of the ward Occupational Therapists at high school about twenty years previously and felt that he got special treatment as a result. "*And I feel that they eventually did well by me. I had criticism of them to begin with, but they did well in the end.*"

He was keen to accept all the help and support he was offered: "*I think I cooperated well, I mean one of the things that I would say is that if anybody is trying to help you, you should listen to what they tell you and do what you're told (.) because they're telling you that for your own good (.) and not feel that you can't manage or you're too able and you don't need this, that or the other thing.*" His rehabilitation was tailored to his interests of football and golf, such as kicking a ball in the physiotherapy gym, and putting. He was discharged after three and a half weeks with daily input to get him back on his feet and to assess his needs at home and how much his wife was able to offer in terms of care. This led to the installation of an extra banister on his stairs and something in the bath which helped him and gave him confidence. He continued to use the support in the bath "*but I could maybe manage without it but I still use it anyway (.) for safety*". He also had a Physiotherapist and Occupational Therapist take him out for walks to improve his mobility and confidence, extending the distance every day towards the golf course. In hospital he used a Zimmer, then two sticks, then one stick. At home he still had the stick although he no longer used it, but it was there if he needed it. He gradually extended his walking distance towards his golf club, with his goal being to play golf again.

*End*

Participant 5 said "*I don't think I was (affected by my stroke), well, mentally I don't think I was (.) And physically I don't think I was either (.) because I probably would of been (.) in the same state physically by ageing as I would when I took the stroke. That's my opinion anyhow*".

He thought that his eyesight and his speech had been affected in the longer term, but his coordination had returned to normal and he was still able to play golf, although he could not hit the ball as far as he could before. He viewed these as “*slight complications*”.

He had always been quite fit, playing 18 holes of golf a couple of times each week before his stroke, even in winter. Since his stroke he stopped at 9 or 12 holes, before he got tired, although he stressed that he could play more if he wanted to. He suspected he might have made this change by this time anyway even if he had not had his stroke. He said that he did not drink so much alcohol now, and he ate less, but again thought this may be due to age rather than stroke as his mother’s appetite reduced as she got older too. “*I think, I think some of it might be due to the stroke, but most of it is just getting old. I’m 83 now, so I can, I can hardly expect to be running about kicking a football or something like that heheh.*” He paced himself: “*If I’m working in the garden I do an hour at a time, rather than staying for the whole morning or something like that. (.) And if I’m playing golf I don’t go out in the garden afterwards. I just take care that I don’t do too much to hurt myself.*”

Participant 5 was trying to make sense of how he survived his stroke, and had a few theories: “*How much I contributed to that (regaining consciousness), I don’t know, I was probably lucky to be in the situation where I wasn’t hit too badly, and I was able to use any resources or strength I had (.) to fight against it. You can get situations where you can do nothing. I was lucky I got somewhere that... my family’s backing for me. The minister actually came in and said a prayer for me, you know, maybe that helped as well, I don’t know heh*”. He thought that going to church helped his wife cope, but he did not feel any emotional benefit from this himself, although he admitted that there might have been a helping hand in his recovery. He drew on his determination throughout his life, for example in his football and golf, which he thought had helped him cope. He said “*I’ve been lucky to survive and even if I’m playing golf and missing puts, heh heh, I’m lucky to be there to miss them*”.

He described that since he was about 70 he had the attitude that “*I always view it as we’re only here for a wee while and I reckon that, getting past 70, everything else is*

*a bonus (.) so if anything does happen to me, I won't say, 'Why me?' I'll say, 'Why not me!' I think that's a better attitude, and you've more chances of succeeding if you do that."* He felt this change was through age rather than his health problems.

Emotionally, *"I tend to be (.) fairly easy going. I don't have highs and lows, and it (stroke) didn't bother me one way or the other."* When asked if he had been frightened, he said *"No, I didn't want to be, heh, it didn't worry me. Eh, I felt that I've a lived a reasonable time and if anything happened now I can't complain (.) Just take things as they come"* – an attitude he has had since his cancer three years ago. His health problems had made him *"realise I'm lucky to be alive"*.

He enjoyed watching TV, reading, gentle gardening and playing golf, similar to before his stroke. *"Yeah, it hasn't affected me at all. I haven't let it. As far as I'm concerned I had a stroke in the past. I mean, when I had the radiotherapy after the cancer what I did, I asked the surgeon and I also asked the professor at (cough) the (hospital), can I tell people that I had cancer rather than I have cancer? They said yeah, so I thought that was a better way to go on. I didn't conceal from anybody that I had cancer or I'd had a stroke. (.) I mean I didn't go round balling it out to everybody but (.) some people hide these things or feel ashamed of being ill or something, but it's a natural process."* He was very conscious of his health now and made sure he took his pills and attended his checkups.

He recalled comparing himself to others with cancer when he was in hospital for radiotherapy, and thought *"I'm lucky I'm not like them"*, but when in hospital after his stroke he was in single room most of the time and did not notice other people. When he was moved to a shared bay, he was not sure what was wrong with the other people.

When talking about his wife and children he said *"I probably value them more than I did... it's probably drawn us closer."* He suspected that his family had *"probably realised my mortality more than they did. And eh (cough) they must have realised that I'm not going to last forever, and ah (.) my days are numbered."* He explained that his family discussed these things as there was no use hiding something, although these conversations have become more frequent and open since his stroke. He

praised his wife for doing very well looking after him, and she had to do more for him now. She was not very well herself sometimes, so they helped each other as much as they could.

## **Participant 6**

### *Personal context:*

Participant 6 lived at home with his two pet birds, who were great companions. He was keen to tell his story but was anxious, especially about getting muddled up with details and not finding the right word, or being able to pronounce it.

### *Interpersonal context:*

He was nervous but very keen to give something back. He told me at the initial meeting that he was often frustrated by his word finding difficulties and requested that he was not prompted, preferring extra time and a pad of paper to make notes for himself. He requested that his ex-wife, who was a good friend and his main support, be present during the interview in case he got muddled up or got details wrong, and to help with his nerves about taking part. He checked details, especially about time with his ex-wife. The narrative was therefore a co-construction between three people. I found myself being much more active during this interview, checking out that I had understood correctly, and asking for clarification more frequently than in the others.

### *Societal context:*

Participant 6 was a hard working man who had embraced a productive retirement. Since his stroke he was unable to work, around his own home or doing odd jobs for others. I had the sense that he felt forgotten by society, and by people in his local area since his stroke. He did not seem to have a role anymore.

### *Beginning*

Participant 6 had worked hard all his life in manual jobs. Since retirement at age 65 he did odd jobs for people in the local area, such as gardening, making more money than he had working full time. He was a very independent man who did not take kindly to being told how he should do things. He was a keen gardener and won awards for his flower beds. He also enjoyed going on holidays regularly. He had heard of stroke but did not know what it meant or anyone who'd had one.



## *Middle*

Seven years ago participant 6 was in a local shop and tried to speak but couldn't. "*I just walked oot the shop.*" When asked what that felt like, he said "*Umm felt a bloomin fool heh*". He went to see his GP and asked what had happened. He described being told that "*Something went wrong*" and that "*aw you'll be alright*". He did not recall being told it was a stroke or receiving any treatment "*I cannae mind what they said it was (2) that long ago huh*". He gradually improved and was back to normal within a week or two. He did not think any more about it.

Nineteen months prior to interview he came home from shopping to find his house on fire. The emergency services had cordoned off the area and he was not allowed inside. He was visibly upset recalling this, bouncing his feet on the ground, hunched over as he said "*They put me in the police car*". His kitchen and living room were destroyed and everything else was dirty and stinking from smoke. He was devastated by this and moved in with his ex-wife and her new husband while his house was being repaired. He stayed there for six months, but felt uncomfortable as he did not have a good relationship with his ex-wife's husband. While staying there, fourteen months prior to interview he had been visiting his son and had another small stroke.

Three months prior to interview (ten months after being home again) he was at home alone and felt unwell. He had a third stroke. He tried to phone for help but the numbers got muddled up. He was in an acute stroke ward for three weeks and a rehabilitation hospital for a month. While in the rehabilitation hospital he was mobile and enjoyed pushing other patients about in their wheelchairs. He got a row for this from the nurses but the physiotherapists said "*not to say anything (.) let him alone.*" He had been home again for six weeks at the time of interview. He found it difficult to remember the details, seeking clarification from his ex-wife, and was upset recalling the details, shaking his head saying "*I've had a rough time of it*".

*End*

Participant 6 described himself as very limited since his most recent stroke: “*Well it’s clear, you couldnae dae things you could normally do for years. Just couldnae do it. Nap. Flummoxed.*” He said “*Well, I cannae do anything... doing the garden, things like that, I can’t do it*”. His legs “*just don’t work*” and everything takes a lot longer to do. He now cannot maintain his garden but “*there’s nothing I can dae aboot it*”. When asked how he feels about that he said “*>sick<*.” He also said that “*age doesnae help (...) I just thought it’s things that’s happening. Ma legs go, pain in ma back, that’s happened me (2) and I got pain in ma leg (2) since 79 I’ve been at the doctors all the time.*”

He also felt unable to go out very much now and when asked if that was also because of his legs he said “*No, not ma legs (.) just (.) cannae (.) be bothered*”. He found this puzzling as he had never felt any pain with his strokes and could not understand how he was so limited without being sore. They went for short day trips on a train now instead of holidays. He described losing his confidence, using an example of being able to walk to the shops if he wanted something before his last stroke but now was not able to. He described his speech difficulties getting him down “*I just cannae pronounce the words right.*”

These experiences were all wrapped up in low mood, and he was attending a psychiatric day hospital one day a week to help with that. He was seeing a speech and language therapist there and had a good relationship with one of the nurses who he could open up to. He also attended a day centre twice a week, where he enjoyed playing dominos and bingo. Other than that he spent most of his time sitting at home, watching wildlife programmes on television, which allowed him to follow his life-long interest in nature and plants. In good weather he enjoyed sitting in his greenhouse and “*I try to dae wee things.*”

When talking about how he used to be an active person he said he’s “*>STUCK!< And that’s what I cannae understand, I don’t have pain or anything, I just >beat<*.” This upsets him. He described two serious episodes of depression while in hospital and one since coming home again.

He described himself as useless in that “*I just cannae dae anything, I tire and I get angry at mysel. (2) I go oot there and I’ll go to the garden and I’ll be cursing and swearing because I’ll be falling all over the place.*” He described not having anything that gave him a purpose now. He also attributed this to his age “*Well, no, I just cannae dae things now, no... And that bugs me... But it’s ma age, cannae do anything else.*”

His ex wife visited two days a week, did his housework and took him to get his groceries. She popped in at other times too. Their son had Asperger’s Syndrome and spent the weekends with Participant 6. When their son was unable to visit his ex-wife tried to take him out so was not sitting in the house alone all weekend.

Although Participant 6 clearly described changes in his relationships, he found it difficult to talk about this. With help from his ex-wife they were able to explain that their relationship had changed. They were more straightforward and honest with each other. She encouraged him to do things rather than just sitting at home. In the past he would have argued with her, but now he didn’t argue back. He had realised that he could not manage independently and that they had to work together. They had fun and use a lot of humour in their conversations. They both wanted to protect their son from the burden of caring for participant 6, which motivated them to make these changes. Participant 6 had a very practical way of thinking about this, to make things easier for everyone.

When describing other relationships he said “*Most of my pals have gone to the other side.*” I asked what he meant by this and he said “*most of them have fallen of old age.*” Although he gets on with people at the day centre, he had no close friends as he had in the past. All of his friends who live nearby “*well, people I thought were friends, well, they couldn’t care less*” following his second stroke. “*You just have to get on with it, that’s all you can dae.*” He used to enjoy going on motor bike trips with a friend and laughingly said he was thinking about getting another one “*Nothing like hoping, right!*” He described always dreaming and hoping throughout life and found that helped get him through.

When asked how he saw himself now he said “*useless,*” but before stroke “*I just never thought about anything. Never bothered about things.*” He was always a private man and in the past would have been ashamed to have depression. He viewed his depression as part of how stroke had affected his brain and had accepted that he needed a bit of extra help by going along to the day hospital. He was able to talk to staff and didn’t keep his feelings to himself anymore: “*I telt the hospital cos it was beating me... I needed help.*” It was difficult for a man who was so independent all his life to admit that he needed help, but he had got through that now. He described that as a big hurdle, but thought “*I was going to do something daft*”. He also described difficulties with anxiety, both worrying when unexpected things happened or things that were expected didn’t happen, although this has improved recently.

Despite being disappointed with the health care he received after his first stroke, he felt well looked after and supported this time, particularly with the CHSS visits.